As a national network of specialist brain injury solicitors and support services, we are used to meeting people affected by brain injury and those who support them in different ways. Brain injury is such a sensitive and complex area that we’ve really come to value the importance of sharing experience and professional expertise across the sector, so we decided to launch Brain Injury News to help do this. We’ve included a range of articles that touch on the spectrum of brain injuries, from mild to traumatic. These cover everyday issues such as welfare and benefit entitlements, through to more sensitive areas like diagnosing a head injury in people with dementia and the ethical implications of caring for people in a persistent vegetative state. Besides our topical guest content we’ve also shared a few details about the Group, what we do and our future plans. We really hope that you enjoy this first issue, and please email lara.king@braininjurygroup.co.uk to add yourself to the mailing list to receive future copies. You can also call 0800 612 9660 to find out more about the Group and how we can support your patients through a brain injury.

Professor Lindsay McLellan
Emeritus Professor of Rehabilitation and non-executive consultant of the Brain Injury Group.
More than 9 out of 10 (95%) people surveyed by the Brain Injury Group said they would welcome a single, online resource signposting them to the services available.

The survey also revealed that nearly three-quarters (69%) of people seeking brain injury information and support turned to their doctor or other healthcare professional to signpost them to the support services they needed.

The BIG Directory now online
In response to this research, the Brain Injury Group has developed an online services directory, The BIG Directory, to provide information and signposting for people affected by brain injury. The directory is free to use and people can browse by category or by area for the help and support they need. You can find it at braininjurygroup.co.uk

“We had long identified the need for a single source directory of services specifically to support people affected by brain injury and our research emphatically reinforced this,” says Sally Dunscombe, director of the Brain Injury Group. “Living with a brain injury is daunting and confusing for families and carers. Our aim is to provide people with an instant, free online signposting service that enables them to find specialist help with ease, saving time and worry.”

Tell your patients about The BIG Directory. You can order free flyers to display in a reception or communal area. Contact us and let us know how many you need: email lara.king@braininjurygroup.co.uk or telephone 0800 612 9660

People with brain injuries and their carers need clear signposting to support services that can help them manage the physical, mental and social challenges they face.

“Our aim is to provide people with an instant, free online signposting service that enables them to find specialist help with ease, saving time and worry.”

How changes and reforms to welfare could affect your patients

BY JAMIE POPPLEWELL, NESTOR PARTNERSHIP

The Welfare Reform Act 2012 will fundamentally overhaul the current benefits system when it is implemented this April. The focus of the reform is to simplify a complex system and provide greater incentives for people to move into work. Many of the reforms affect disabled people and carers.

The two main changes are:

a) Universal Credit (UC) replaces existing means tested benefits and Tax Credit
b) Personal Independence Payment (PIP) replaces Disability Living Allowance (DLA)

PIP will be piloted in the North of England for new claims in April 2013. From October 2013, it will be rolled out for new claims nationwide and UC will replace new claims to Income Support, income based Jobseeker’s Allowance and income related Employment and Support Allowance. This will be followed by the abolition of new claims to Housing Benefit and Tax Credit, which will also be included in UC from April 2014.

DLA will continue in its current form for children until they reach 16 and for those who will be 65 or over from 8 April 2013.

Universal Credit
From October 2013, there will be no new claims to Income Support, Jobseeker’s Allowance (income based) and Employment and Support Allowance (ESA) (income related), as UC is rolled out nationally. From April 2014 there will be no new claims to Housing Benefit and Tax Credits, and the existing claims will start being converted to UC. Under the current system, those with more severe disabilities that have no other adults living with them in receipt of Carer’s Allowance, receive an additional £58.20 in their weekly means tested benefit to help with extra costs.

There will be no equivalent of this “Severe Disability Premium” under UC – this will equate to a loss of over £3,000 a year for a large number of severely disabled people.

Parents who provide care for a disabled child and receive a “Disabled Child Element” under Child Tax Credit will see this abolished and replaced by a lower amount under UC.

Personal Independence Payment
As with DLA, PIP will be made up of two elements, the “Daily Living component” replacing the existing care component of DLA, which has been reduced from three elements to two, and the Mobility component, which will remain largely the same as it is under DLA. Each will be paid at either a standard or an enhanced rate. Removing the lower level of the care component will effectively mean those that have less severe disabilities, but still require some form of care or assistance, will be entitled to less – a loss of over £1,000 a year in current terms.

Under PIP, disabled people will be assessed using much the same principles as with the current Work Capability Assessment for ESA. There will be a medical assessment, in which claimants will be assessed on how their health condition impacts their ability to undertake specified daily activities. Each activity awards a number of points; it is expected that a claimant will have to gain 8 points to achieve the Standard rate and 12 points to be awarded the Enhanced rate. Unlike the existing DLA criteria, which is widely open to interpretation, the activities under PIP are very rigorously defined.

“Parents who provide care for a disabled child and receive a ‘Disabled Child Element’ under Child Tax Credit will see this abolished and replaced by a lower amount under UC.”

Nestor Partnership is a specialist independent financial advice firm. They work with the Brain Injury Group and can provide people affected by brain injury with a financial advisor to:

- review their financial position
- identify welfare and benefits entitlement
- manage any urgent problems
- investigate any opportunities to claim from existing insurance policies.

Find out more at braininjurygroup.co.uk/benefits-and-brain-injury
Managing older people who sustain an acute brain injury in the context of an underlying cause for cognitive impairment or dementia can be complicated. A relatively trivial head injury, in the presence of co-existent brain atrophy, anticoagulant medication or aspirin, can result in an intracranial bleed. This frequently occurs in the subdural space and causes acute or gradual increasing pressure on the brain, presenting as worsening of the individual’s cognitive ability. As the head trauma can be very mild it may go unnoticed and so vigilance is required.

Symptoms will also be exacerbated as older patients may become gradually more drowsy and therefore more susceptible to dehydration poor nutrition and poor compliance with their medication.

Assessing a head injury in patients with cognitive impairment
Clinical assessment of the severity of a head injury can be particularly difficult in patients with underlying cognitive impairment, as the symptoms will frequently be identical to those of other causes of dementia.

These overlapping symptoms include:
• inability to remember the cause of the injury or events that occurred immediately before or up to 24 hours after
• confusion and disorientation
• difficulty remembering new information
• trouble speaking coherently
• changes in emotions or sleep patterns.

However, new complaints which should alert the observer to a possible recent head injury include:

Older people, specifically those with cognitive impairment, are at increased risk of sustaining a brain injury, mainly through accidents and falls.
For older people, even without previous cognitive impairment, the direct effects of the injury may result in disproportionately high levels of long-term cognitive changes, reduced ability to function and changes in emotional health.

**Evaluating outcomes**

Evaluation of outcome should include:

- questions about the circumstances of the injury and pre-existing cognitive status and an assessment of activities of daily living
- assessment of the person’s post trauma level of consciousness and confusion
- neurological examination to assess memory and thinking, vision, hearing, touch, balance, reflexes and other indicators of brain function
- imaging, initially with a CT scan, to assess for haemorrhage, brain swelling and skull fractures – if there is generalised brain swelling from acute injury it may not be possible to assess underlying brain atrophy (shrinkage) related to dementia.

**Treatment and outcomes**

Most traumatic brain injuries are mild and can be managed with either a short hospital stay for observation or at-home monitoring followed by outpatient rehabilitation.

In order to design an appropriate, cost-effective, integrated multidisciplinary rehabilitation programme, it is essential to:

- obtain an accurate clinical and physical therapy assessment of the individual’s challenges
- understand the occupational and social challenges for the individual and their family/carer
- have a formal detailed assessment of the person’s cognitive capability.

Over the past 30 years, some research has linked moderate and severe traumatic brain injury to a greater risk of developing Alzheimer’s disease or another type of dementia, years after the original head injury.

One of the key studies showing an increased risk found that older adults with a history of moderate traumatic brain injury had a 2.3 times greater risk of developing Alzheimer’s disease than older people with no history of head injury. Those with a history of severe traumatic brain injury had a 4.5 times greater risk.

It is suspected that traumatic brain injury causes changes in brain chemistry that affect levels of beta-amyloid and tau proteins, which are also linked to Alzheimer’s disease. In addition, it is hypothesised that individuals with a variation of the gene APOE-e4 may be at greater risk of dementia should they sustain head trauma.

“This strategies for treating Alzheimer’s disease or another specific type of dementia are the same for individuals with and without a history of traumatic brain injury.”

Ideally, this should be co-ordinated by a neuropsychologist who can continually monitor the delivery of appropriate services, according to the individual’s changing physical and psychological/cognitive needs.

Treatment of dementia in a person with a history of traumatic brain injuries varies depending on the type of dementia diagnosed. Strategies for treating Alzheimer’s disease or another specific type of dementia are the same for individuals with and without a history of traumatic brain injury.

Educational and support meetings for relatives and carers are extremely important in helping carers and family to understand and optimise the longer term management of individuals of all ages, with brain injury, especially in the context of co-morbid cognitive impairment.

Brain injury and the risk of dementia in older patients

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This article was provided by Re:Cognition Health, a specialist provider of clinical services to all types of patients with cognitive problems.

Email: clinician@re-cognitionhealth.com
Twitter: @ReCogHealth
Advances in neuroimaging and neurorehabilitation are transforming the landscape for clinicians involved in treating patients with disorders of consciousness.

Clinicians need to remain aware of how these technological advances impact on ethical and legal factors associated with treating patients diagnosed with disorders of consciousness, particularly where end of life decisions and advance decisions are concerned.

Patients with disorders of consciousness include those:
- in a coma
- in an unresponsive wakefulness state (also known as a persistent/permanent vegetative state)
- in a low awareness state (also known as a minimally conscious state)
- with a functional locked in syndrome.

Distinguishing between disorders of consciousness can prove challenging, not least as patients may progress from one to another – for example, from an unresponsive wakefulness state to a minimally conscious state as they recover. Misdiagnoses of an unresponsive wakefulness state have been estimated at around 40%.

Increasingly sophisticated diagnostic technologies, improved neurorehabilitation strategies and guidelines on the withdrawal or withholding of treatment face clinicians with complex ethical and legal decisions. This is exacerbated where patients have made advance decisions refusing lifesaving treatment should they be diagnosed with a condition resembling unresponsive wakefulness state or low awareness state.

Under the Mental Capacity Act 2005, clinicians must give effect to advance decisions refusing lifesaving treatment created when the patient had decision-making capacity, recorded in the form specified and applicable to the clinical situation described in the advanced decision. Where patients can be reliably diagnosed as incompetent, or lacking decision-making capacity without hope of recovering this, as in an unalterable unresponsive wakefulness state, following guidelines on the withdrawal of treatment or advanced decisions is relatively straightforward.
As the competence of patients in locked in syndrome typically remains unaffected, they are able to continue to take decisions over treatment.

However, patients in a low awareness state and the technological advances associated with this diagnosis present clinicians with a range of dilemmas. While there has been some success in using neuroimaging to communicate with them, what this means and how it relates to means of assessing decision-making capacity now and in the future is unclear. Yet the possibility of ascertaining their current wishes and preferences as regards treatment exists (Mackenzie, 2013). How this should affect the duty imposed under the Mental Capacity Act to maximise incompetent patients’ input into decision-making, or the requirement to take their previous wishes and preferences into account, remains unsettled. Baker J in a recent Court of Protection case about withdrawing treatment from a low awareness state patient, Re M [2011] EWHC 2443 (Fam), recognised that the current and past views and values of such patients were likely to differ. What weight should be placed on past and present wishes in these circumstances is uncertain, though this may potentially be resolved through a consideration of their best interests.

“Increasingly sophisticated diagnostic technologies, improved neurorehabilitation strategies and guidelines on the withdrawal or withholding of treatment face clinicians with complex ethical and legal decisions.”

Clinicians are obliged to follow a patient’s advanced decision refusing life-saving treatment only where they are satisfied that it is valid and applies to the patient’s clinical situation. Given how recent the diagnosis of low awareness state is, patients are less likely to have specified this condition in an advanced decision.

Even where low awareness state has been specified in an advanced decision, the caveat in the Mental Capacity Act that advanced decisions refusing life-saving treatment should not apply when conditions have changed since they were written suggests that advances in communication via neuroimaging and neurorehabilitation potentials may alter clinicians’ obligation to follow such advanced decisions.

It is important for clinicians working in this field to keep up with all the ethical and legal factors associated with treating patients diagnosed with these disorders of consciousness in order to provide appropriate treatment.

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**Glossary**

**Coma**
A state of unarousable unresponsiveness where there is no evidence of self-awareness or environmental awareness. Eyes are continuously closed, purposeful responses to environmental stimuli cannot be elicited and there is no evidence of discrete localising responses or language comprehension and expression.

**Unresponsive wakefulness state**
A diagnosis of unresponsive wakefulness state [UWS], previously known as persistent or permanent vegetative state [PVS], indicates a state where there is a complete absence of behavioural evidence of awareness of self and environment, coupled with a preserved capacity for spontaneous or stimulus induced arousal. This means that the patient is wakeful, but NOT aware or conscious.

**Low awareness state**
A diagnosis of low awareness state [LAS], also known as a minimally conscious state [MCS], indicates a condition of severely altered consciousness in which minimal but definite behavioural evidence of awareness of self or environmental awareness is demonstrated. The diagnosis must be supported by limited but clearly discernible evidence of awareness of self or environment, demonstrated on a reproducible or sustained basis.

**Locked in syndrome**
A diagnosis of functional locked in syndrome [LIS] is applied to patients who show non-behavioural evidence of consciousness or communication only measurable via para-clinical testing (i.e. functional MRI, positron emission tomography, EEG or evoked potentials).

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**Further reading**


Support for brain injured people

The Brain Injury Group is a unique legal network that brings together the best quality legal advice with specialist support and benefits for your patients and their families.

What makes us distinct from others is that all our members are dedicated brain injury solicitors with a proven track record in handling brain injury cases, one of the strict criteria we set for them to join the Group. This is teamed with a range of specialist support services that are provided free when one of our solicitors is appointed:

- a family co-ordinator to assist at times of crisis.
- a case manager to carry out an urgent initial needs assessment.
- a financial advisor to review the financial position, help manage any problems and investigate opportunities to claim from existing insurance policies.
- guidance in identifying and applying for welfare and benefits.
- a statutory funding advice service.

Your patients can discuss their circumstance in confidence through an initial consultation, which is free of charge and without obligation.

We are also pleased to offer general information and signposting to anyone affected by brain injury on the main helpline number 0800 612 9660 and via our website braininjurygroup.co.uk

Helping to rebuild lives

Jacqueline Pike, 40, was driving with her four children when she was hit head on by another car in February 2008. She sustained multiple injuries, including several broken bones and a brain injury that has left her in a wheelchair.

Jackie spent a total of 22 months in hospital, firstly in intensive care, then on the ward followed by rehabilitation care. She now lives independently, but relies on a live-in nanny to help with the children, plus a carer who assists with day-to-day tasks around the house. Her brain injury has left her disabled, with difficulty speaking and greatly impaired co-ordination.

Jackie is a single parent so for the last four and a half years, her two brothers and aunt cared for the children. The children were all separated, with her daughters Vicky and Nicola returning home in 2010, but her sons, Daniel, now 15 and Robert, 14, have yet to return.

Now, five years on, Jackie, 45, is soon to have her family reunited in a specially adapted home near Bath. The high cost of her rehabilitation, home adaptations and professional carers is being covered by the compensation secured for Jackie by her Brain Injury Group solicitor, Neil Elliot of Thrings. We are delighted that the family will be back together shortly.

Keep up to date

For the latest news, topical issues and best practice articles, sign up today to receive your next copy of Brain Injury News, which will be coming out up to three times a year. You can also subscribe for monthly e-updates that include a round-up of the latest media coverage on brain injury.

Email lara.king@braininjurygroup.co.uk to put your name on both lists.

Also find out more at our healthcare professional pages braininjurygroup/hcp

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To find a local solicitor who can help your patients, search our members map at braininjurygroup.co.uk