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Welcome

Rehabilitation is a critical part of the recovery process for anyone who’s experienced a brain injury. Experts agree that, generally, the earlier the intervention the greater the benefit. However, the form rehabilitation takes, how it’s funded and maintained long-term – as well as how success is measured – are open to argument and interpretation.

In this edition of Brain Injury News, a number of professionals involved in the care and rehabilitation of people with traumatic brain injuries share their views and experiences. A common theme throughout is that teamwork is the key to achieving the best outcome.

Collaborative working is enshrined in the Rehabilitation Code, a benchmark for approaching personal injury claims developed by the legal and insurance sectors some 15 years ago. Our feature includes a best practice case study of working to the Code (page 6), together with opinions from both sides of the claims fence on how the Code works, and commentary on why it is now being reviewed (page 8). Clinical psychologist Dr Neil Parrett shares his view of collaborative working on page 9.

We also look at the statutory support and funding available for brain injured people, and the welfare benefits available to support a return to work. Both articles and a very personal case study demonstrate clearly that knowing your way around these complex systems is vital if you want to access them.

We welcome your views on these topics and any brain injury related issues. To find out more about the Brain Injury Group, please visit our website at www.braininjurygroup.co.uk or give us a call on 0800 612 9660.

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Avoiding social isolation after a brain injury

Professor Lindsay McLellan considers the role family, friends and colleagues can play in rehabilitation.

The severity of a traumatic brain injury (TBI) is traditionally assessed on the basis of the duration of unconsciousness, or of post-traumatic amnesia, immediately after the event. Categorised in this way, most people who have had a ‘minor’ TBI recover and rehabilitate themselves without intervention. But a significant number of those with a minor injury, and almost all those with more severe injuries, are likely to benefit from formal help.

The impairments caused by a TBI range from physical (such as paralysis and clumsiness) to cognitive (particularly difficulties with memory, concentration and ‘frontal lobe’ functions). Some cognitive impairments, such as problems with decision-making, judgement, insight, and the integration of thinking and feeling, can have a strong impact on personal relationships and communication. Physical problems rarely persist without accompanying cognitive and behavioural changes, but these changes are often present in people whose mobility and coordination have returned to normal.

Numerous surveys have confirmed that input from close friends and relatives is vitally important for a person’s morale during recovery. Therefore it’s essential to have an assessment by a specialist brain injury rehabilitation service that incorporates formal neuropsychological assessment, and that also works closely with family members.

Improving neurological function through activity
After a TBI, continuing to engage in appropriate activities (including social and recreational activities) can improve neurological function over many months and, if necessary, years – well beyond the time anticipated for other neuropathological conditions such as stroke. This may be because TBI tends to cause diffuse neuronal damage, in which connections between neurones across wide areas of the brain are disrupted although many of the neurones are still alive. These damaged neurones can reconnect only if stimulated by frequent use. If no guidance is given, whether from health professionals or family, and inappropriate behaviours are allowed to continue and be ‘practised’, they may become the new ‘norm’ and be hard to reverse.

Reinforcing social connections
It is often assumed that the faster a person can return to full activity and employment, the better their recovery must have been. However, significant impairments of judgement, insight and emotional intelligence may not be obvious early on when the recovering person’s focus is on the need to build up stamina and overcome fatigue. For example, it may not be until the student is able to return to the mental and social challenges of university, or the adult well enough to return to the rigours of work or join friends in a complex social environment, that the full extent of their impairment becomes apparent to others – let alone to the person themselves, as their insight may have been subtly impaired.

Without the right preparation and guidance, which often involves delaying return or restricting the demands of work initially, the student may unnecessarily fail their course or the employee lose their job, and close personal relationships come under severe pressure. The injured person may feel isolated, misunderstood, angry and depressed and once in a hole like this, it can be very difficult to retrieve them.

The support of family and friends during rehabilitation is essential both for optimising performance and minimising the risk of depression, unemployment, family breakdown and progressive social isolation.

Professor Lindsay McLellan
Emeritus Professor of Neuro Rehabilitation at Southampton University, is a long time advocate of adopting a joined-up approach to care. He is a non-executive consultant of the Brain Injury Group.

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BRAIN INJURY NEWS

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Rehabilitation services: How the UK compares to Europe

This figure presents a comparison between the four biggest countries in Europe in terms of the number of hospital beds, of neurologists and of rehabilitation specialists per 100,000 inhabitants. The last graph presents the cost of all brain disorders per patient (in Euros purchasing-power parity). The data is from different open access sources with different time periods reported.

The UK has the lowest number of hospital beds (ratio 1/2 compared with the three other countries), neurologists (ratio 1/5) and rehabilitation specialists (ratio 1/10), however the cost of brain disorders per patient is greater mostly due to the high level of indirect costs.

References
3 White book on physical and rehabilitation medicine in Europe produced by the UEMS Section of Physical and Rehabilitation Medicine 2006

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The Rehabilitation Code in practice

Developed jointly by insurers and claimant lawyers in 1999, the voluntary Rehabilitation Code provides a framework to help all those involved in a claim work collaboratively. After 15 years and with a review pending, we hear how the Code can work from the professionals who put it into practice. We also hear why it’s being reviewed.
In September 2010, Adam* was driving with his 17-year-old daughter Charlotte* to an owners’ club rally in his sports car. His car came off the road and collided with a parked Land Rover. Sadly, Adam was killed in the crash and Charlotte suffered catastrophic injuries that left her with significant brain injuries as well as multiple physical injuries.

Charlotte spent months in a high dependency unit and was in state of minimal consciousness for many weeks. She underwent post-acute rehabilitation at The Children’s Trust, Tadworth, but it was very clear that she would require care and support for the rest of her life.

With no other vehicle involved in the accident, Francis Lacy Scott, representing Charlotte, and David Harrison, the claims manager acting for Adam’s insurers RSA, set about working together at a very early stage to manage the claim. Their primary concern was to enable Charlotte’s rehabilitation to be maximised, and to attend to the immediate financial needs of her family. Full liability was admitted early in the process, and there was no question that compensation would ultimately be made available to support Charlotte throughout her life.

This case embodies the principles of the Rehabilitation Code which requires both the claimant solicitor and the insurer to “treat the possibility of improving the client’s quality of life and their present and long term physical and mental wellbeing, as issues equally important as the payment of just, full and proper compensation”.

Joined up working
Francis and David jointly instructed Professor Udo Kischka, a leading consultant in neuro rehabilitation, to undertake an initial assessment and to consider the rehabilitation and care Charlotte required immediately and in the short term. He undertook further assessments as her treatment progressed.

Regular multi-disciplinary meetings of the treating medical professionals involved in Charlotte’s care at Tadworth, which also included Francis and Professor Kischka, ensured that everyone knew what she needed, and what was required of them. Francis met regularly with David to report on her progress. Between them, they were able to establish what Charlotte and her family needed, and make sure it was provided.

A series of early interim payments provided funds to deal with practicalities such as buying equipment not available from the NHS, adapting the family’s accommodation to enable Charlotte to be cared for at home during breaks from Tadworth, and to buy a special vehicle for the family. One of the key investments of the interim payments was the addition of a specialist brain injury case manager to the support team.

Knowing that the case was being managed collaboratively and proactively was a great comfort to Charlotte’s family. It offered both relief and reassurance, and the knowledge that her care needs would be funded privately for life allowed them to focus on her recovery and rehabilitation.

Facing the future
Given her injuries and initial prognosis, Charlotte’s exceptional progress continues to defy all expectations. She still experiences cognitive and mobility problems and has support for most of the day, but has the potential to live independently with an established support team in place. Now aged 21 she has started a three-year course at the National Star College, an independent specialist further education college for people with physical disabilities, acquired brain injuries and associated learning difficulties.

Charlotte’s story clearly demonstrates how well the Rehabilitation Code can work for all parties and that the collaboration of the legal and insurance sectors and the medical team with primary care responsibilities can improve the outcome for clients on many fronts. Being able to fund early intervention and ongoing care addresses many of the practical issues involved in a client’s rehabilitation, but being able to work in partnership to deal with those matters quickly and efficiently also gives the client and their family the comfort and confidence that reduces unnecessary stress in an already intensely challenging situation.

* Names have been changed.
A lawyer’s perspective...

In over 20 years of looking after clients who have suffered traumatic brain or personal injury, the early stages of a claim are dominated by the immediate needs of the client and their family. The potential for a big settlement is, quite rightly, far from anyone’s mind. What families are looking for is an assurance that they will be able to access the best possible support and rehabilitation for their loved one – and pay for it and other immediate needs if necessary.

Serious injury claims take a long time to settle, and invoking the Rehabilitation Code may provide the opportunity for a claimant to access funds early in the claims process, which may not otherwise have been available, and speed up the potential for rehabilitation and recovery. It can also relieve the worries and fears of the family to a degree, and create a positive climate to negotiate a sensible final outcome.

Implemented in the right spirit, with both parties adopting an ethical and professional approach to collaboration, the Rehabilitation Code can be hugely beneficial to both claimants and insurers. Creating a climate of trust and partnership is crucial to achieving those benefits, and the introduction of the Code in 1999 went some way towards alleviating the sometimes antagonistic ‘them and us’ stance taken by claimants and defendants, which might have precluded sensible negotiated settlements.

The case study opposite is seen by both lawyers and insurers as a best practice example of how the Rehabilitation Code can work to everyone’s benefit. It illustrates how it is based on mutual trust, integrity, honesty and common sense.

Regrettably, I have also witnessed situations where defendant insurers have, contrary to the spirit of the Code, exploited for tactical advantage the earlier access to detailed medical evidence that the Code allows. As a voluntary mechanism, it’s never going to be perfect. However, there is no doubt in my mind that the Code has helped an awful lot of people who might otherwise have been floundering in their search for the right kind of support.

Francis Lacy Scott
is a partner at asb aspire LLP and recognised as a specialist in high value catastrophic injury claims.

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An insurer’s perspective...

At RSA, we fully support the Rehabilitation Code to promote early intervention so that the injured person makes the best possible recovery. Early rehabilitation is an important step in the recovery process: it ensures that the claimant is the focal point for both insurer and solicitor, and our experience is that the earlier the intervention, the better the outcome.

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It is vitally important for both sides to work collaboratively to achieve the maximum benefit for the claimant. The Code encourages us to work together to identify an appropriate person to carry out an Immediate Needs Assessment (INA); we are keen for this to be arranged as soon as practicable, to enable timely intervention.

Open and honest discussion is paramount. If joint instruction of the case manager can be agreed, funding is easier to obtain as the compensator is kept fully informed and is able to make decisions. Joint instruction also promotes healthy debate.

At the very least, there should be ongoing disclosure of case management reports and medical records.

Our experience reflects that of Francis Lacy Scott: many solicitors will work collaboratively, but others do not enter into the spirit of the Code. Following the jointly instructed INA, for example, they will unilaterally appoint a case manager and are often reluctant to release progress reports and refuse our input into the process beyond requesting interim payments.

This approach deprives the insurer of information on which to make decisions on funding and, in circumstances where the claimant is not receiving 100% of his compensation, it will inevitably mean that the claimant is funding treatment themselves which could be funded under the Code.

The Rehabilitation Code provides the opportunity to place the claimant at the centre of the process, to ensure that treatment is provided swiftly, with optimum recovery at the forefront of everyone’s mind. We have many experiences of early rehabilitation achieving excellent results for claimants, and a collaborative approach between the parties invariably achieves the best outcome.

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RSA
Key features and benefits

The Rehabilitation Code promotes the use of rehabilitation in the compensation process so that the injured person makes the best and quickest possible medical, social and psychological recovery. It provides a framework to ensure the early assessment of an injured person’s needs, whatever the nature of their injuries, and the delivery of appropriate rehabilitation so that their health, quality of life and ability to work are restored as far as possible before, or alongside, the claims process.

Key features

- the injured person is at the centre of the process
- all parties to a claim must co-operate from the outset to address the needs of the injured person
- the potential for rehabilitation is addressed as a priority, initially outside of the litigation process and often before the claim is resolved
- rehabilitation needs are assessed by those with appropriate experience, qualifications and skills, often by an expert agreed by both parties
- the insurer will pay for any rehabilitation that is recommended – a refusal to pay must be justified and, if the claim is unsuccessful, the cost cannot be recovered

Benefits

- early intervention and rehabilitation should enable the injured person to achieve the best recovery possible
- the insurer may benefit by a reduction in the financial value of the claim due to the improved outcome for the individual

Reviewing the Rehabilitation Code – moving with the times

The Rehabilitation Code has changed the personal injury culture for the better and become embedded within the claims process. It is widely accepted by lawyers and claims handlers and regarded as useful.

Yet, for all its undoubted value, the Code is showing its age. The legal framework, the provision of care by the NHS and the attitudes and practices of insurers and lawyers have all changed significantly since it was last reviewed seven years ago. The IUA-ABI Rehabilitation Working Party, which oversees the Code’s progress, has concluded that the document needs an overhaul if it is to remain relevant.

We are looking particularly at four areas:

1) Should the document distinguish between different levels of injury, something it has not done up to now?

2) In particular, should there be a fundamental change in its approach to lower-value claims, acting as a guide to best practice as well as providing a legal framework?

3) Should the Code continue to stop at the Immediate Needs Assessment? Or should the principles of the Code be extended to the treatment itself?

4) We are looking to put together a short guide around how case managers are instructed so that all parties understand each other better.

As a highly complex area with its own special requirements, the people best placed to advise us on this review are those at the front line. We encourage professionals involved with brain injury claims to contact us with their views.

Mark Baylis chairs the IUA-ABI Rehabilitation Working Party.

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“The IUA-ABI Rehabilitation Working Party, which oversees the Code’s progress, has concluded that the document needs an overhaul if it is to remain relevant.”
For clinical psychologist Dr Neil Parrett the road to recovery starts with building the right care team. Here he shares his views on approaches to rehabilitation.

As a clinical psychologist who specialises in community-based rehabilitation, and having worked in the statutory, private and charity sectors, I have witnessed a wide range of approaches to rehab – some good, some bad, and some downright dangerous!

Insurance-backed settlements in brain injury cases provide access to opportunities that are simply not available to people seeking support exclusively through statutory or charity settings. However, they also present their own challenges. These are the top three issues I face on a regular basis:

Setting up the rehabilitation team
This is clearly a crucial stage for any rehabilitation programme and one area which the NHS, due to its funding limitations, has simply had to learn to deal with. A range of variables such as the client’s readiness for rehabilitation and availability of funding play a key role.

Where rehabilitation is being funded privately, it is just as critical to establish a clinician lead and a coherent, integrated, goal-directed programme from the outset. My own experience suggests that having a clinician who knows how to lead from the start could probably save thousands of pounds of input trying to resolve the issues that allowing people to ‘just get on with the job’ creates. Personally, I find it disheartening to be asked to join a team with support workers already in place and a full range of professionals all doing their own thing.

‘Experts’
I do some work as an ‘expert’ as well as being a treating clinician, and it never fails to astound me how many supposed experts don’t have any actual ‘hands on’ experience of community-based rehabilitation. Experts, particularly neuropsychologists, tend to be the types who love tests and measures and rules and regulations. ‘Real life’ neuro rehabilitation, however, is a very different kettle of fish to the theoretical. Certainly the treating team can (and probably will) measure away, but as long as there is an integrated, goal directed programme at its heart, that should be good enough.

Less really can be more
I appreciate that the aim of pursuing a third party claim is to achieve the best possible outcome for the client, but sometimes I have been left wondering ‘at what cost?’. The implicit pressure on the patient/client, their family and, to a degree, the treating team, to instigate the maximum intervention and support package possible can sometimes be both unhelpful, and potentially harmful.

Psychologically fragile individuals can, through no conscious process, be guided to a place where they end up more impaired than they might otherwise have been without a large financial settlement pending, and when the litigation is over, those problems can and will remain.

The bottom line? Yes, early intervention undoubtedly has benefits, but the key to rehabilitation is treating the individual. We shouldn’t be afraid to take a bit longer or do a little less if that reduces the pressure on the client and improves the ultimate outcome.

Although obviously biased, I’d recommend getting a treating psychologist with community rehabilitation expertise on board early, and leave them to work with the case manager to maximise the client’s rehabilitation potential.

Dr Neil Parrett is an HCPC registered clinical psychologist. Currently lead clinician for brain injury rehabilitation at Re:ognition Health, he has previously worked for Blackheath Brain Injury Rehabilitation Unit, Hothfield Manor Brain Injury Unit and the RNRU Outreach Team.

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Seven years ago, Stewart Newman suffered a devastating brain injury in a road crash. He spent five years in various London hospitals. His mum Lynne describes the ongoing challenge of getting Stewart the support he needs, which inspired her to set up her own brain injury charity.

At the beginning, I felt Stewart’s care and rehabilitation plans were taken out of my hands by hospital and Primary Care Trust staff. It wasn’t clear what was available to us – I just had to go where I was told to go and had little say in the matter.

Stewart did have some excellent care, but I can’t help feeling he wasn’t in the most appropriate wards for much of the time. He spent time on stroke wards and general medical wards where I felt the staff didn’t fully appreciate the care of brain injured patients. It’s why I’ve been campaigning for specialist brain injury wards and hospitals to be built.

Stewart is paralysed down the left side of his body, he uses a wheelchair and needs round-the-clock attention. Two carers each take a 12-hour shift; an additional carer visits three times a day to help him change and shower. We didn’t want Stewart to go into a care home. He said hospital was like prison and begged us to bring him home. We were granted funding for his continuing care and he returned home to us in April 2012. But it’s a battle to keep this funding.

Now he is in a loving environment Stewart is calmer and no longer thrashes about when we try to help him. However, this improvement has led to the Clinical Commissioning Group (CCG – formerly the Primary Care Trust) marking him down to the point they want to remove continuing care. All the other aspects of his high-level needs remain unchanged, and we simply can’t afford to pay social services for the level of care he needs. It’s a huge worry.

My family and I, together with Social Services, have spent months appealing the CCG’s decision. Stewart is completely funded and that’s the only way he can live at home. The cost of residential care would be far higher than continuing care at home and we will keep fighting for his funding.

“We were granted funding for his continuing care and he returned home to us in April 2012. But it’s a battle to keep this funding.”

Lynne Newman is one of five women who set up Brain Injury is BIG – a charity offering understanding and support to the families of those affected by serious brain injury.

Access their online forum at www.braininjuryisbig.org.uk or call their helpline on 01483 770999 (9am – 9pm).
Sourcing the right support for a brain injured person requires knowledge of statutory and local services – and some serious juggling skills. Sarah Ransome shows the benefit of combining statutory and private provision.

There is no doubt that the care provided in acute trauma centres is fantastic, but it’s no surprise that outpatient rehabilitation varies widely across the country. Although evidence suggests timely rehabilitation intervention for people with brain injury significantly improves their prospects of recovery and reduces the likelihood of further admission (and cost) to the NHS, it is difficult to predict the efficacy of the rehabilitation care people will receive locally once they’re discharged.

To get the best out of the system, you need to know how to find your way around it. People who have suffered a brain injury aren’t generally in a position to do that themselves. However, the right service from the right provider can ensure the most positive outcome possible is achieved.

Bethan’s story
Bethan sustained a traumatic brain injury during a road traffic accident. Her inpatient rehabilitation was excellent, but she struggled to continue her progress when she returned home and tried to maintain her previous family and social roles. Bethan struggled with these roles, and particularly with parenting her young son. She was fatigued, and her rehabilitation progress all but stopped. Rehabilitation from her local Clinical Commissioning Group (CCG) was time limited, and she relied heavily on family support for her daily living needs.

Identifying the right support
Our case management assessment delivered a holistic view of Bethan’s pre-injury situation, her current circumstances, and the impact caused by her injuries. We identified areas where early intervention was recommended and the areas most important to Bethan; we looked at the treatment and support required, and its likely cost. Our knowledge of the respective roles and responsibilities of both social and health care services meant that we were able to help her access the appropriate services from each department.

We helped her to access social care assessment following which Bethan was able to acquire equipment to support her at home, and also to employ a support worker to assist with her personal care and daily living needs. Crucially, the support worker was also tasked to support Bethan with looking after her son. We identified other universal services open to her, for example signposting local day care and toddler clubs. With support in place, Bethan was able to structure her week so she could be with her son but also leave time, space and energy for rehabilitation.

We helped Bethan to access the rehabilitation support that was available locally through the CCG, and used privately funded services to plug any gaps.

Finding your way accessing funding and services

“We helped Bethan to access the rehabilitation support that was available locally through the CCG, and used privately funded services to plug any gaps.”

It is possible to access health and social care support, but negotiating the system can be tricky – and frustrating – and some knowledge of your rights under current legislation and the division of responsibilities will make things quicker.

Clearly a holistic approach at the outset also means that requests for support can be targeted to the right funding streams and services in the first instance, and by taking this line with Bethan we were able to put together a care plan that met her own priorities whilst getting her back on her rehabilitation path.

Sarah Ransome is Senior Operations Manager at Independent Living Solutions (ILS), which provides specialist case management and rehabilitation services.

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The benefits system has seen a massive shake-up in recent years, and it’s easy to imagine that people who need transitional support might be denied it. However, there is still flexibility within the system to provide reassurance and support to people with brain injuries who are keen to return to work, as Lee Ryan explains.

Returning to work after a brain injury can be overwhelming, especially if you are still experiencing health problems. But financial pressures mean many people claiming benefits don’t have a choice. There are several avenues back into work however, that don’t have an immediate or negative impact on the benefits payable. For claimants to decide on their best course of action, they need to know about the options available and the likely effect on benefits of a structured return to work.

Work experience: If a claimant has received benefits for a long period or if they need to consider an alternative path because of the long-term impact of a brain injury, they may want to consider work experience in an area they’re interested in. The Department for Work and Pensions actively encourages work experience as a gateway back into employment, and it can be done whilst still receiving benefits.

Permitted work: This route allows benefit claimants to try out work within certain limits. Permitted work earnings at the lower limit will disregard £20 per week for means-tested benefits, and up to £101 per week at the upper level before benefits are affected. Helpfully, there is no time limitation for permitted work.

Part-time work: Another viable option might be to go part-time. Depending on the number of hours worked, this could lead to entitlement to tax credits to supplement earnings, as well as help with rent and council tax payments. Receiving a qualifying benefit, such as Disability Living Allowance (DLA), or Personal Independence Payments (PIP) may entitle a claimant to additional tax credit elements, thus increasing overall income.

Disability-related benefits on return to work
Disability Living Allowance (DLA), Personal Independence Payments (PIP) and Attendance Allowance (AA) are payable regardless of whether or not someone is working. They are not means tested, but starting a job may, in certain circumstances, suggest that care or mobility needs have changed leading to them being reduced or stopped. It really depends on the type of work undertaken, but in many cases they will not be affected.

Employment and Support Allowance (ESA) or Incapacity Benefit (ICB) will stop when a claimant starts work, but it’s worth remembering that entitlement to these benefits can be re-established if a claimant stops work within a 12-week period. This effectively gives claimants a chance to try returning to work again, safe in the knowledge that they can go back to their previous level of benefit within 12 weeks if things don’t work out, and without having to re-apply.

Evidence suggests that moving from benefits to employment proves a positive step for many. Returning to a work environment can help claimants avoid isolation and improve their self esteem. It may also be a chance to socialise more, learn new skills, and become more active in their community. Overcoming the fear factor of getting back to work can therefore be hugely beneficial, especially if allied with expert advice on what ‘in-work’ benefits are available.

Working out how best to structure a return to work is the key to minimising the impact on a person’s benefits and can help make sure it happens in a way that suits their individual needs.

Lee Ryan is a Welfare Benefits Consultant with Nestor, an independent financial advice company with many years’ experience in the complex personal injury field.

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