Returning to Work after a Brain Injury & Stroke:

Confusion for All, Elephants in the Room & Busting Common Myths

Dr Giles Yeates, Consultant Clinical Neuropsychologist

Mandy Salter, Neuro Occupational Therapist, Specialising in ABI Vocational Rehabilitation

Martin Hillier, Disability Employment Consultant

Returning to work following an acquired brain injury should not be rushed and requires delicate planning around the survivor, their job role and the work environment. This can be a confusing and daunting experience for both survivors and their employers/colleagues, with many of the impacts on working life hard to discuss openly during the return to work process. Here a team of experienced providers of neuro vocational rehabilitation bust important myths and name those elephants in the workplace.

We have worked together for over 10 years in a highly-specialised NHS service providing vocational rehabilitation for people who have sustained an acquired brain injury (ABI). ABI in adulthood is a sudden onset of brain damage that does not progressively worsen over time at the physical level. Common forms of ABI include traumatic brain injury (often from road traffic accidents, falls or assaults), and stroke (ischaemic – a block or haemorrhagic – a bleed, involving the blood vessels feeding the brain oxygen and glucose). Other forms of ABI include infections such as encephalitis or meningitis, hydrocephalus, oxygen starvation, brain infections and recover after brain tumour treatment. While at a physical level the damage does not worsen over time, many survivors are left coping with ongoing difficulties with mobility, thinking and memory, emotions and communication/relationships, and managing these at home, in the community and in the workplace.

Returning to work following a brain injury or stroke is a key aim for many survivors, a marker of recovery and a return to normality. For their managers and colleagues at work, there is also enormous good will and desire to support this return to work asap. The survivor of injury may have played a pivotal role in the company/organisation for many years before the injury, their skills are valuable and also many close working relationships and friendships have been developed over the years (many of us spend more time in our lives with our work colleagues than our family or other friends). Many employers too are committed to supporting disability in the workplace, in line with the Equality Act (2010) and their own values, and commitments such as the Disability Confident Scheme.

As three professionals working as a team with both the survivor and their employers to make this a reality, we have seen how this initial good will can change over time to a very confusing experience for all concerned. As such, we want to share our experience with employers (managers, colleagues), occupational health providers, and employment health insurers. We have listed 5 key issues that are either myths/assumptions held by those supporting survivors back to work, that often do not hold up over time, or are unspoken elephants in the room that challenge all involved from the shadows:

Challenge 1: Myth - A phased return to work after brain injury or stroke is similar to other health conditions

Brains are complex and unique parts of the body. They do not heal in the same way as a broken bone or torn muscle. The degree of recovery in the workplace (i.e. the ability for the employee to resume all of their duties, perform well and be satisfied in their role) is dependent on the type of brain injury, which parts of the brain have been damaged, but also the interaction of these factors with the unique work environment in your organisation and the work role itself.

Many employers and occupational health providers are used to incrementally-increasing hours and responsibilities in during a phased return to work. However recovery and performance after brain injury can be really impacted by fatigue from mental stimulation and sensory processing issues. As such the incremental stages of a phased return to work may be shaped by increasing the business of the work environment, contact with other employees, including a key element of home working, or implementing a unique schedule of activity and rest. Importantly, reviewing progress through phases of return to work and making decisions about upping demands needs to be guided by experts in brain injury/stroke rehabilitation.

Challenge 2: Myth - It is all about physical supports in the workplace.

Common adjustments in the workplace for disability may be physically-focused such as ergonomic chairs, desks and computer equipment. While these are important, many survivors of brain injury and stroke find that the more disabling aspects of the environment are noise, lighting, background conversation, or how cluttered the workspaces are. Difficulties in processing information quickly and filtering out unwanted information mean that every little thing, object, sign, and noise all comes flooding into the mind of a survivor, filling it up and overwhelming them. These needs may have different impacts on the ability to carry out the role, and the adjustments required, depending if the role is in an office environment, customer-facing, an industrial or construction setting.

Workspace adjustments and changes to work practices for both the survivor and their neighbouring colleagues may require unusual steps compared to other health conditions, to allow the survivor to allocate all of their mental resources on the job role itself and optimise their performance and contribution to your organisation. Some of these changes are counter-intuitive and require guidance from brain injury professionals. Thinking outside of the box is required.

For example, we supported one survivor to successfully return to a scientific research role only by them working from 4am to 11am, doing their core tasks in the early hours of the morning free of distractions before their colleagues arrive, and then joining key morning meetings to link with others before they finish their working day. A radical return to work plan for a desk-based job, but it meant their role, productivity and performance was optimised and retained.

Challenge 3: Myth - Once an initial return to work has been successfully completed, job done!

This is a key false assumption that we have encountered many times, and links to the previous myth – many people think that there is a final point of recovery for survivors and a return to work functioning that requires no further support. Indeed, many UK government-contracted disability employment organisation are focused on getting the person back to work, with no longer-term follow-up. Someone who has reached an equilibrium of functioning and performance at work may have done so on a foundation of subtle adjustments and work role/environment conditions/support, many of which are delicate and can be easily undermined.

The three of us have taken pride in our unique role in being there for both survivors and employers in the months and years following the initial return to work, as new or repeating needs come up once more. This is what we have learned in playing this long-game:

Think of a house of cards. When the initial components of a return to work are put in place and the survivor is doing well for a period of months following this, all actually rests on the delicate balance of needs, conditions and practices that support this success. This fragile balance can be inadvertently disturbed in many ways, the house of cards collapses, and both survivors and employers can be plunged back into a state of crisis, confusion and distress. Changes that disturb the balance can be a physical change in environment (e.g. moving to open plan office layout, the presence of construction works in the adjacent building), or more commonly work personnel (often a change in a line manager after many successful years can lead to a crisis for the ABI survivor, as their new manager is communicating in a different way or does not have the benefit of accumulated knowledge of supporting brain injury in the workplace). A change in the work role itself that may seem to be minor to some may be too drastic a leap for the survivor who is managing cognitive difficulties in memory, attention or planning/organisation.

Change of any kind can be much harder to manage, adjust to, flexibly-respond and update for survivors of brain injury and stroke. Each new change requires a reconvening of the employment support network to plan, support and ideally anticipate to guide the change process in a way that is minimally-disruptive for the survivors.

In addition, there are two elephants in the room that are rarely talked about in conversations between employers and disability employment professionals, and so lurk in the shadows to cause problems for all concerned:

Challenge 4: Elephant in the Room - Changes in social behaviour for survivors and impact on colleagues

Research on return to work after brain injury and stroke (including a study we have published ourselves) has shown that the factors that are associated with loss of a job role or demotion are not the core ability to do the technical aspects of the job role itself, or difficulties in physical or memory abilities. Instead difficulties in planning and organising and empathy/social behaviour for survivors are the key danger points.

These post-injury difficulties can show themselves as not putting things into place that have been verbally agreed, missing deadlines and letting colleagues down. In addition, the job performance may be fine, but during coffee breaks, a survivor may inadvertently make their colleagues feel offended or uncomfortable by saying inappropriate things or invading personal space. Subtle and unspoken rules in the workplace can be easily broken, such as not using a colleague's mug, or unspoken rules around dress when there is a non-uniform policy. Office politics can be difficult aspect of work to negotiate at the best of times, but for a survivor of brain injury or stroke, can get out of hand and social transgressions can frequently occur. Sometime, essential strategies used by survivors to manage their time at work can attract negative judgments from others. For example, many survivors use their lunch breaks to leave the office and go somewhere quiet, to manage fatigue. This can often be seen as 'anti-social' by others in the workplace.

From the perspective of the survivor, the responses and actions of colleagues (who are offended or uncomfortable but this is not clear to the survivor) can be confusing and unpredictable, and a source of anxiety, distress and feeling powerless to change to situation.

For the line manager/employer these issues can be really hard to manage. Having a conversation about socially-embarrassing incidents is much harder than talking about an aspect of the job itself. Difficulties with walking or even memory can be seen as a disability, but inappropriate behaviour can be hard to view in the same way (often talked about as an attitude, motivational or personality problem). Even if this can be linked to disability following a brain injury, good intentions to support the survivor often clash with the feelings and needs of other employees who may be affected by the inappropriate behaviour of the survivor. If a whole team is complaining about one individual, disability or no disability, this can be a really difficult situation for a manager to handle.

In our experience, it is these post-injury changes and needs that are the hardest to openly discuss in meetings between employers, HR, occupational health and brain injury professionals. As such their occurrence can't easily be anticipated or responded to. From the clinician's perspective, the employer seems to be saying that everything is ok then suddenly wants to shift to discussing disciplinary proceedings, work capability routes and termination of employment, without a middle ground.

Challenge 5: Elephant in the Room – Giving feedback

Survivors of brain injury, struggling with memory difficulties, joining the dots together when problem-solving, adapting to change and empathically picking-up on the social cues of others, need feedback. They don't know what they don't know, and are working things out as they go along. Coping with the impact of the brain injury at home does not necessarily prepare them for doing the same at work. So to get on the same page as everyone else, survivors needs to be told (supportively but directly) what is different now, what is not working out as anticipated and what needs to be done differently.

On the other side, work colleagues may really struggle to do this, worrying about the feelings of the survivors, or struggling to cross a boundary or work hierarchy and give feedback to someone who is/was in an equal or more senior role. It is a really hard situation for both potential receiver, and provider, of feedback. However as a result, feedback doesn't happen at all and problems can persist and grow to a point of no-return. If a problem is picked up quickly when it first occurs, both the survivor and their employer can learn how to adapt and manage a problem in enough time to stop things escalating to the point of compromising the job role and employment. The initial unfamiliarity of providing direct feedback can save the loss of a job later-on.

However the provision of feedback in the ideal manner will vary across work settings, line management structures and job roles. This may also be influenced by decisions taken by both survivor and their manager as to how the details of the survivor's injury and workplace needs are shared in different ways around the organisation. Deciding who, and how, to provide feedback, can be complicated, and ideally this should be developed with input from brain injury and disability employment experts.

So, there we have it – 5 challenges (myths and elephants in the room) that have been the source of struggle for survivors of brain injury or stroke, their employers/managers, their colleagues and those who support them.

There is a bigger picture here too for both employers and survivors – people go to work for the job itself, their career, to get paid and to have good working relationships with colleagues. They do not go to work to offer a healthcare service for someone with complex needs and the survivor themselves wants to be seen as a competent employee, not a walking disability. At the same time, survivors often have to juggle work-life balance following brain injury, with issues such as fatigue meaning that all their energy and resources may be focused on doing a good job during work hours and as a result, being a shell of a person when at home. The bills are being paid but no-one is happy, some may be acutely struggling behind the scenes.

If these ideas are relevant for you as an employee survivor of brain injury/stroke, colleague or employer and you require more support, there are useful links to free resources below. A useful collaboration can be facilitated between a community neuro-rehabilitation/stroke clinician (e.g., an occupational therapist, speech and language therapist or clinical neuropsychologist), occupational health and the employer, although specialist NHS vocational rehabilitation services are rare in the UK.

Our Interdisciplinary Work Support Service

We are a unique team of clinicians and disability employment experts that have provided specialist vocational rehabilitation services for over a decade. In comparison to a single vocational rehabilitation profession, our team approach brings a rich, multi-perspective that links the worlds of work and rehabilitation. We uniquely specialise in supporting people to retain their work role post-injury, and respond to new changes and challenges over time, in addition to the initial return to work phase post-injury.

We can intervene quickly to employment situations via our *Brains@Work Crisis Response*, supporting both the survivor and their employer. This process involves neuropsychological and work environment assessment, job role profiling, close liaison with employers, occupational health, human resources and workplace health insurers. In addition, we will work to support the wellbeing of the survivor themselves and help them manage their work role within the bigger picture of their wider health and social needs, liaising with other healthcare professionals involved. We offer this service nationally in the UK and around the world. For more information on accessing our services, see: http://www.ripplingminds.com/relationships-in-the-workplace--vocational-rehabilitation.html or contact: drgilesyeates@gmail.com

Links & Resources:

Access to Work (Governmental scheme in the UK to support people with disabilities and their employers, part-funding reasonable adjustments)

https://www.gov.uk/access-to-work

Disability Confident (Department for work and pensions scheme for employers regarding good practice for employers)

https://disabilityconfident.campaign.gov.uk/

Returning to Work after Brain Injury:

https://www.headway.org.uk/media/4130/returning-to-work-after-brain-injury-factsheet.pdf

https://www.headway.org.uk/media/4123/brain-injury-a-guide-for-employers.pdf

https://www.headway.org.uk/media/4989/brain-injury-a-guide-for-colleagues-factsheet.pdf

https://www.headway.org.uk/media/4125/making-a-complaint-about-treatment-at-work-factsheet.pdf