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An expert opinion: Vocational rehabilitation after stroke

Key messages

- Ask the work question and start vocational rehabilitation early after stroke.
- Invisible symptoms pose particular challenges for the return to work process.
- Increased commissioning of resources is required to provide equitable and timely access to vocational rehabilitation services.

Abstract

Less than half of people return to work following a stroke. For those who do, their return is often complicated by residual 'invisible' symptoms. It is important to ask about work and to provide intervention early in the rehabilitation process. Specialist vocational rehabilitation services can support more complex and long-term interventions, but there is a paucity of service provision which needs to be addressed.

One in four strokes occur in people of working age.¹ Return to work is often a key goal for the person with a stroke and important for maintaining quality of life and wellbeing.² However, less than half of those in employment return to work after a stroke.²

Why do so few stroke survivors return to work?

Many factors may present barriers to returning to work. These include the stroke location, severity of symptoms, skills and demands of the job role, work culture and type of industry, and employer's attitudes to disability. There are often complex relationships between these factors and understanding the impact of disease-related factors within the employment context, and the wider psychosocial situation, is key to addressing return to work. The job role may significantly influence the impact of any impairment. For example, a taxi driver may not be able to return to work with a hemianopia, whereas an office worker could.

'Invisible' symptoms pose particular challenges for the return to work process and sustaining employment. These include fatigue, cognitive changes, aphasia and visual impairment. Invisible symptoms may be difficult for employers to understand

and to make accommodations for. The person with the stroke may not anticipate their impact on their ability to work. Fatigue is a common symptom that is often underestimated. This may result in a premature return with an unsustainable work pattern, leading to further sickness absence or job loss. Cognitive impairments may have wide-ranging effects. For example, executive dysfunction can manifest in difficulties with planning and problem solving, insight and awareness and social cognition. Such symptoms can lead to diminished work performance and, if not addressed, carry risk to the person's job security and to the business.

The psychological impact of stroke also influences return to work. Psychological sequelae including post-traumatic stress, anxiety, low mood, confidence and adjustment issues, and maladaptive coping styles may all contribute to poor outcomes. Negative self-appraisals of 'being unable to perform as well as before' can activate beliefs around incompetence and failure that, without skilled intervention, can perpetuate cycles of avoidance and worsen outcome.

Employer factors, such as the size and scope of the organisation and its willingness to be flexible, can be highly influential to the outcome. There is increasing government drive for employers to support people with disability in work,³ but this may present complex issues for employers and many lack knowledge and experience.⁴ The broader social context is also relevant and lower socioeconomic status is associated with an increased incidence of stroke. Stroke survivors may be less likely to have secure job contracts and income protection insurance, increasing their risk of job loss.

What help is available to support return to work?

Some people with mild symptoms can successfully return to work unaided or with minimal signposting and advice. Many others will require vocational rehabilitation to return to and remain in work, or to leave work in a supported way. Vocational rehabilitation can be provided by post-acute and community stroke rehabilitation teams and specialist vocational rehabilitation services. However, provision of vocational rehabilitation for stroke survivors in

the UK has been disorganised and patchy.⁵ Some community teams are structured to provide vocational rehabilitation as an adjunct therapy, but others lack the resources or perceived expertise to provide this. The early supported discharge model may only be resourced to intervene for a few weeks, and this may fall short of the longer term demands of a return to work intervention. Specialist NHS vocational rehabilitation services can provide more complex and long-term interventions but are scarce and, with demand frequently out-stripping capacity, may not always be able to intervene in a timely manner.

Aside from NHS resources, help may be available through generic occupational health services or private vocational rehabilitation services, although usually only accessed through an employer or insurance company. The government provides other work support including Jobcentre Plus and Access to Work, but these do not provide comprehensive vocational rehabilitation programmes. Employment support services are available through third sector organisations both nationally, such as Attend ABI and Scope, and regionally, such as Leonard Cheshire and Shaw Trust, but these usually cannot provide complex multidisciplinary interventions. The Stroke Association also provides helpful guidance on returning to work after stroke.⁶

What is the recommended approach to vocational rehabilitation?

There is little evidence to guide best practice in vocational rehabilitation. Only one randomised controlled trial, which reported benefits from workplace interventions, has been completed,⁷ and systematic reviews have found insufficient evidence to make recommendations.^{8,9} Despite this, there is growing recognition of the need for a systematic approach to vocational rehabilitation following stroke. The NICE quality standard for stroke states that adults who have a stroke are offered active management to return to work if they wish to do so.¹⁰ The Royal College of Physicians National Clinical Guideline for Stroke recommends commissioning of specialist vocational rehabilitation services in accordance with their guidance (Table 1).¹¹

When should vocational rehabilitation start?

The importance of having the work conversation and starting vocational rehabilitation early after stroke is increasingly recognised.¹² Vocational rehabilitation should start as soon as feasible after the stroke, and not be deferred to when the person wishes to return to work. Informed discussion about disclosure and early communication with the employer should be encouraged. Key areas to be addressed in the early phase are suggested in Box 1.

The need for early and integrated vocational rehabilitation after stroke is acknowledged in the NHS Long Term Plan.¹³ An inte-

Table 1. Stroke rehabilitation: recommendations for work. Adapted from the Royal College of Physicians National Clinical Guideline for Stroke.¹¹

National clinical guideline for stroke: recommendations for work
A. People with stroke should be asked about their pre-stroke work activities.
B. People who wish to return to work after stroke (paid or unpaid employment) should: <ul style="list-style-type: none"> – have their work requirements established with their employer (provided the person with stroke agrees); – be assessed cognitively, linguistically and practically to establish their potential for return; – be advised on the most suitable time and way to return to work, if return is feasible; – be referred through the job centre to a specialist in employment for people with disability if extra support or advice is needed; – be referred to a specialist vocational rehabilitation team if the job centre specialist is unable to provide the necessary rehabilitation.
C. Vocational rehabilitation programmes for people after stroke should include: <ul style="list-style-type: none"> – assessment of potential problems in returning to work, based on the work role and demands from both the employee's and employer's perspectives; – an action plan for how problems may be overcome; – interventions specifically designed for the individual which may include: vocational counselling and coaching, emotional support, adaptation of the working environment, strategies to compensate for functional limitations in mobility and arm function, and fatigue management; – clear communication between primary and secondary care teams and including the person with stroke, to aid benefit claims or to support a return to work.

Box 1. Key areas to address with early vocational rehabilitation

- Ask the work question as part of systematic acute stroke screening
- Signpost to advice on disability and employment rights
- Manage expectations to avoid premature return to work
- Communicate with the employer to provide education and manage expectations
- Establish links between post-acute, community and specialist vocational rehabilitation services

grated post-acute stroke rehabilitation service is to be piloted and vocational rehabilitation is a key requirement, with pilot sites expected to provide support for at least six months. This early input is welcome but, for some people, it may be several months before they are ready to focus on returning to work, and so access to vocational rehabilitation must still be available in the longer term.

Which disciplines are required?

Stroke may result in a range of neurological impairments, and there may be other associated medical issues. Therefore, a multidisciplinary team is required, with core disciplines including occupational therapy, neuropsychology, speech and language therapy and neurology/stroke/rehabilitation medicine. Although there is no evidence for a multidisciplinary approach in vocational rehabilitation, there is some evidence for this approach with other rehabilitation interventions.¹⁴

The multidisciplinary vocational rehabilitation out-patient service at the National Hospital for Neurology and Neurosurgery was established in 2013. It is one of just three specialist neurological vocational rehabilitation services in London. It supports people with acute and progressive neurological conditions with return to work (paid and unpaid employment), job retention and supported exit; about one third are stroke survivors. The service has dedicated occupational therapy, neuropsychology and neurology, and direct access to other disciplines.

In our experience, multidisciplinary assessment aims to develop a thorough formulation of a person's stroke symptoms and pre-morbid factors, beliefs about work, level of occupational performance and baseline cognitive functioning, as well as job demands and the social and physical environment. This process is key to understanding the individual's unique needs and interventions required.

Which interventions are useful?

There is insufficient evidence to definitively recommend specific interventions. In our opinion, interventions should be individually tailored and focused on functional goals identified collaboratively with the stroke survivor. The primary goal is usually returning to work with adjustments. Therefore, establishing and maintaining relationships with the employer is key to the process,⁴ and interventions may need to continue after the point of return to facilitate a sustained outcome. Some may achieve their goals with short-term uni-disciplinary interventions such as implementation of strategies to self-manage symptoms. Others,

Box 2. Common vocational rehabilitation interventions

- Job demand analysis: leading to work hardening and task simulations, to help build insight and highlight any difficulties prior to returning to work.
- Establishing the right timing for return to work.
- Developing a plan for graded return to work, working hours and duties, and reasonable adjustments.
- Neurological fatigue assessment and education: to pro-actively manage symptoms through behavioural change and attitudes to rest.
- Providing emotional support to address adjustment issues, anxiety and the impact of the stroke on the individual's sense of identity and ability to work in the same way as before.
- Understanding cognitive strengths and weaknesses and developing compensatory strategies specific to the individual's working role.
- Exploring difficult work relationships and promoting psychological strategies to manage these.
- Educating the employer regarding the condition, invisible symptoms and stroke recovery.
- Empowering the individual to communicate about their stroke and changing needs with their employer.
- Meeting with the individual and employer to establish expectations and the employer's willingness to support the return to work and explain rationale for reasonable adjustments.
- Monitoring return to work and exploring alternatives where current work is not feasible or cannot be sustained.

particularly those with complex invisible symptoms and reduced insight, may require various facets of multi-disciplinary intervention over the longer-term (Box 2). Managing the person's expectations and supporting the evolving adjustment to their situation is a central aspect throughout the process. If job demands outweigh the person's new capabilities, the goal may change to a supported work exit with interventions focused on exploring meaningful activities to replace work and ascertaining financial stability.

How should outcome be measured?

It is important to measure outcome to assess efficacy of interventions and support development of services. Vocational rehabilitation is a difficult area to measure and there is a lack of robust outcome measures. Even return to work is heterogeneous in nature and not a defined outcome.¹⁵ Some employment programmes focus on return to work as the main outcome and cease intervention when the person starts back at work. In our experience, this is not helpful and may lead to premature return to work, breakdown in the process and risk of sickness absence or job loss.

What are the future priorities?

The priority for stroke vocational rehabilitation is to increase commissioning of resources to provide equitable and timely access to services. Research into the most effective service models, interventions and outcome measures is also essential. A multicentre randomised controlled trial to assess the effectiveness of early stroke specific vocational rehabilitation is currently underway in the UK,¹⁶ and it is hoped that there will be further such robust trials. In the meantime, stroke services should adapt their clinical practice to raise the work question early and to establish pathways with existing vocational rehabilitation services.

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