

**MASCIP**

Multidisciplinary Association for Spinal Cord Injury Professionals

# Vocational Rehabilitation Guidelines 2017

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## Foreword

As Chair of the Vocational Rehabilitation Association, I am delighted to see the MASCIP Vocational Rehabilitation Guidelines, and to recognise the important place they have in the promotion of vocational rehabilitation as an essential part of a healthy work environment in the UK.

The total economic benefits of rehabilitation are increasingly acknowledged around the world, but - shamefully - the UK is still lagging behind in the implementation of good rehabilitation policies. Documents such as the MASCIP Guidelines do much to bring this anomaly to the attention of policy makers, and the Vocational Rehabilitation Association will be using them to emphasise the importance of good vocationally-focused rehabilitation practices.

As active members of the Council for Work and Health, the Vocational Rehabilitation Association will promote the Guidelines to all Council for Work and Health affiliate members, and therefore ensure they are read and understood by many thousands of rehabilitation practitioners.

The Vocational Rehabilitation Association, alongside MASCIP, will also publish the guidelines on its website, with a strong recommendation for its own members to study them closely, and to benefit from the clear direction taken in the various sections

John Pilkington – Chair, Vocational Rehabilitation Association. July 2017

## Introduction

MASCIP, the **Multidisciplinary Association for Spinal Cord Injury Professionals**, aims to provide a national professional forum to promote standards in clinical practice, foster research and encourage the development of health and social care services for people with spinal cord injuries.

These guidelines are for practitioners and managers working with people with spinal cord injury and in particular those working in UK spinal cord injury centres. The aim is to set out good practice in vocational rehabilitation; to support and guide evidence-based service development and ultimately to improve return to work rates after spinal cord injury in the UK.

Key issues uncovered through the consultation and literature search for this document were:

- Available evidence suggests that only around a third of people with spinal cord injury in the UK go (back) to work after their injury (that's from the lucky ones that get access to specialist spinal cord injury rehabilitation).
- Being employed is extensively evidenced to be of huge benefit to physical and mental health and is furthermore a good indicator of how someone is coping and adjusting. Conversely, being out of work is extensively evidenced to be a huge risk to physical and mental health.
- At the time of writing, most of the specialist NHS spinal cord injury centres offer some sort of back to work support, but it is **inconsistent** and tends not to be integrated or proactive; vocation often isn't seen as a core focus. Most of the centres **don't understand their level of need** for vocational support, **or track the outcomes** of the work they are doing. Many rely on charities to provide most of the support.
- Charities find it a challenge to engage users in vocational support after discharge. They report that many injured people and their families and friends, even after specialist inpatient rehabilitation, **believe that work isn't possible, desirable** or necessary for them because of their spinal cord injury, and therefore don't take up services that exist to help them achieve this. There is commonly a belief that they have nothing desirable to offer a potential employer, and a well-founded fear of rejection and discrimination.
- Many **staff working in the centres believe that it's too early** to talk to people about work, being unaware of the extensive evidence around early intervention. Many staff tell us they **don't have enough resources**, and **lack confidence** in how to support people.
- Where people have a legal claim relating to their injury, the **legal system is seen as a huge barrier** to people working, by injured people and professionals alike.
- Despite these challenges there is a real opportunity for change. The NHS England Clinical Reference Group for spinal cord injury (now part of the Spinal Services CRG) identified vocational rehabilitation as a **priority area for improvement** in their five year plan to 2019, as did the NHS England Service Review December 2016. And there has been a great deal of appetite from staff across the UK for more guidance and to be able to achieve more. **Evidence-based good practice** is available, together with some examples of what's been tried in the sector.

We hope the guidance on the following pages helps you to make a difference whatever your role. We encourage all MASCIP members to familiarise themselves with these guidelines and use them to support their practice in whatever area of spinal cord injury management they are involved in. Please let us know how this document helps you, what else would be useful, and how you get on with implementing any changes. For any queries, please contact MASCIP (see [www.mascip.co.uk](http://www.mascip.co.uk)).

**Stef Cormack**  
**MASCIP Committee**  
**July 2017**

## Key recommendations checklist

- ✓ Vocational goals are integrated into the whole rehabilitation process and all key structures and systems (e.g. multidisciplinary working, goal setting, reviews, discharge planning, post-discharge support)
- ✓ Vocational rehabilitation is integral from day one and beyond discharge. By discharge the aim should be that the patient and their family (and employer / potential employer):
  - have every chance of believing that work is possible and can be beneficial
  - are linked into proactive, ongoing support beyond discharge to help them to achieve this goal, both from the SCI centre and from other sources such as local agencies and SCI charities
- ✓ A named lead for vocational rehabilitation is appointed to coordinate multidisciplinary efforts, with appropriate training and authority
- ✓ Needs are assessed (at an individual and patient population level)
- ✓ Vocational outcomes are tracked beyond discharge
- ✓ Awareness is raised amongst all staff coming into contact with the injured person and their family from day one, so that all are prepared to reinforce that work is possible and beneficial, that much can be done to support people (back) into work and are clear how to refer on for further support
- ✓ Vocational support begins from the early stages and continues right through beyond discharge, working in partnership with other stakeholders
- ✓ The vocational navigator tool and role recommended by the Royal College of Occupational Therapists is made use of
- ✓ Peer support organisations are involved in vocational rehabilitation
- ✓ Awareness is raised amongst staff of what can and should happen where a patient has a legal claim. Staff are encouraged to be steadfast and determined in their efforts to support people (back) to work regardless of legal advice offered

## 1. What is Vocational Rehabilitation?

The UK government has summarised vocational rehabilitation simply as: ***‘whatever helps someone with a health problem to stay at, return to and remain in work’*** (Waddell, Burton & Kendall, 2008). The British Society of Rehabilitation Medicine (BSRM) has a similar definition but one which also specifically includes helping people to access work initially (BSRM, 2000)

For more detail, this definition is based on the World Health Organisation International Classification of Functioning: ***‘Vocational rehabilitation is a multi-professional evidence-based approach that is provided in different settings, services, and activities to working age individuals with health-related impairments, limitations, or restrictions with work functioning, and whose primary aim is to optimise work participation’*** (Escorpizo et al, 2011).

These definitions remind us of the difference we are trying to make: whatever we do we must seek to establish to what extent we are successful. They also focus us on working towards a multidisciplinary, evidence based approach as set out in the guidelines to follow.

Vocational rehabilitation can take a number of forms, three key ones being:

- Preparing disadvantaged young people for the world of employment ,
- Job retention—supporting and maintaining those currently in employment ,
- Facilitating new work for disadvantaged individuals currently out of employment and unemployed or on ill-health benefits (Frank, 2016)

There is now a strong scientific evidence base for many aspects of vocational rehabilitation (Waddell et al, 2008). In a literature review from 1975 to 2006 (Anderson et al, 2007) found that vocational rehabilitation can increase the likelihood of return to work, especially if a change in profession was required.

Vocational rehabilitation will often target people of working age. However, it is also critical that younger people with spinal cord injury are supported by specialists with their vocational plans from an early stage as it is unlikely that local services will have true knowledge of their potential and therefore won't be able to effectively support the young person and their family's aspirations and plans for the future. Participation and meaningful activity are critical goals of rehabilitation for anyone of any age including older people.

## 2. Why is vocational rehabilitation important?

### 2.1 Work and worklessness after spinal cord injury

- It is estimated from available evidence that **only around a third of people of working age return to work after spinal cord injury in the UK** (Kennedy, 2015). This is based on data from people who have had access to specialist inpatient spinal cord injury rehabilitation. Experience from those we've consulted, from one retrospective outcome measurement study (Smith, 2002) and from service user consultation by the UK SCI charities for the NHS England service review in 2016 (unpublished), would suggest that employment rates are likely to be even lower for people who haven't had specialist SCI rehabilitation.

Employment rates after spinal cord injury in the UK are believed to be lower than in the past (Kennedy, 2015) and lower than in other European countries (BSRM, 2010).

Employment and money-related issues are some of the areas with the lowest reported satisfaction for people with SCI, and employment is an even more important factor for life satisfaction than level of impairment or disability (Ottomanelli & Lind, 2009).

Being employed is **extensively evidenced to be of huge benefit to physical and mental health**.

Work is fundamental to the way our society is structured and plays a vital role in most people's lives: 'The right work in the right place, with the right employer, the right tasks, the right hours, the right colleagues and the right support gives us: -

- Social networks and contacts
- Structure and purpose to our time
- Physical and mental activity
- Money
- Skills
- Social status
- Meaning to the concept of leisure' (College of Occupational Therapists / National Social Inclusion Programme, 2007)

In spinal cord injury specifically, as Kennedy (2015) points out, 'The benefits of employment following SCI rehabilitation are well documented and wide-ranging. Being employed is related to greater life satisfaction, better psychological adjustment and improved quality of life, (Ottomanelli & Lind, 2009; Krause et al, 2004; Anderson et al, 2007) as well as fewer secondary health complications (Meade et al, 2011) and increased life expectancy (Krause et al, 2012). The financial independence (either full or part) resulting from employment also contributes to a feeling of personal growth and an increased sense of purpose (Chapin & Kewman, 2001) and purpose in life has been shown to be directly related to positive psychological adaptation following SCI (deRoos-Cassini et al, 2009).'

**Long-term worklessness**, conversely, is extensively evidenced to be a **huge risk to physical and mental health** (Waddell & Burton, 2006), with significantly increased suicide risk (Wessely, 2004; Bartley et al, 2005) and the overall health risk being equivalent to smoking 10 packs of cigarettes per day (Ross 1995). All staff should be made aware of the profound disadvantages of being out of work.

**Employment status can also be a good indicator of how someone is coping** and adjusting:

*'It is evident that being able to maintain employment following spinal cord injury is a strong overall indicator of successful rehabilitation, owing to the levels of physical and psychological health and mobility, and effective skin, bladder and bowel management required to sustain work.'* (Kennedy, 2015)

## 2.2 Case study example of transformational change in vocational rehabilitation in a UK spinal cord injury centre

### Case study example: Using evidence based practice in spinal cord injury rehabilitation

The Golden Jubilee Regional Spinal Cord Injuries Centre at the James Cook University Hospital in Middlesbrough referred to published research on return to work rates in spinal cord injury in the UK (see section 2.1). They also reviewed their local need, completing an audit in 2007 identifying that the return to work rates of newly injured patients in the Northern Region was only 23%. Audit results also indicated that 45% of patients worked in 'heavy' physical intensity occupations (5 point scale Tomassen at el 2000) prior to their spinal cord injury. This was a reflection of the work available within the northern region, thus creating a greater challenge for return to work post spinal cord injury.

In light of this, they reviewed published guidance to redesign their model of vocational support based on the Vocational Navigator model recommended by the Royal College of Occupational Therapists, and all the information together made a solid case for funding for a new staff post to put this into practice.

An occupational therapist was recruited to support people post discharge; working collaboratively with patients to identify goals and barriers. The therapist provides tailored supportive interventions to address barriers and help bridge gaps towards goals.

The centre reports that subsequent audits indicated significant (143%) improvement in the numbers of newly SCI patients (of working age) who returned to gainful employment:

**April 2012-2013 – 49%    April 2013-2014 – 56 %**

At time of writing there were no plans to publish this data however it is an example of how peer-reviewed, published models have been put into practice in a UK spinal cord injury centre and an example of how extra resource for vocational rehabilitation was achieved. All centres are urged to consider their local needs to determine the best way of using the model in their own circumstance; but this is one example that seems to show a very positive impact.

## 2.3 Policy context

### World Health Organisation

The World Health Organisation (2013) views essential measures to secure the right to economic participation as 'including legislation, policy and programmes that promote:

- physically accessible homes, workplaces and transportation;
- elimination of discrimination in employment and educational settings;
- vocational rehabilitation to optimize the chance of employment;
- micro-finance and other forms of self-employment benefits to support alternative forms of economic self-sufficiency;
- access to social support payments that do not act as disincentive to return to work; and
- correct understanding of spinal cord injury and positive attitudes towards people living with it.'

### UK Government Green Paper 2016

The UK Government Green Paper (DWP & DH et al, 2016) stresses a need for clinicians to have ambitions for patients in relation to work-related outcomes and to facilitate their employment aspirations

### The National Service Framework for Long Term Conditions (Department of Health 2005)

The NSF for LTC set out a number of Quality Requirements including one (QR6) for vocational rehabilitation. This states that *'People with long term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities'*.

This quality requirement comes with four 'evidence-based markers of good practice' as follows:

1. Coordinated multi-agency vocational rehabilitation is provided which takes account of agreed national guidance and best practice
2. Local rehabilitation services are provided which:
  - Address vocational needs during review of a person's integrated care plan and as part of any rehabilitation programme
  - Work with other agencies to provide:
    - o Vocational assessment
    - o Support and guidance on returning to or remaining in work
    - o Support and advice on withdrawing from work
  - Refer people with neurological conditions who have more complex occupational needs to specialist occupational services
3. Specialist vocational services are provided for people with neurological conditions to address more complex problems in remaining in or returning to work or alternative occupation including:
  - Specialist vocational assessment and counselling
  - Interventions for job retention, including workplace support
  - Specific vocational rehabilitation or 'work preparation' programmes
  - Alternative occupational and educational opportunities
  - Specialist resources for advice for local services
4. Specialist vocational rehabilitation services routinely evaluate and monitor long-term vocational outcomes, including the reasons for failure to remain in employment

### The ICF, the CHART and the National Spinal Cord Injury database

The Craig Handicap Assessment and Reporting Technique (CHART) was developed to assess the World Health Organisation dimensions of handicap according to the 1980 International Classification of impairment, disabilities and handicap. According to WHO at that time, handicap described the total effects and interplay of all the consequences of disability: social, economic, cultural and environmental. The classification was redefined (WHO, 2001) and became the International Classification of



Functioning, Disability and Health. The WHO now defines disability as a contextual variable, dynamic over time and in relation to circumstances. The CHART, albeit unchanged since 1992, remains the key relevant measure.

As part of the national spinal cord injury database it was agreed that the CHART would be one of the key national standardised outcome measures used in UK specialised spinal cord injury rehabilitation. The CHART is an interview tool, undertaken either face-to-face or by telephone. Multiple measurements can be taken over the course of a person's lifetime to assess changes in adaptation over time after initial rehabilitation. One of the key dimensions of the CHART measures occupation: described as the individual's ability to occupy time in the manner customary to the person's sex, age and culture. The dimension measures gainful employment, education and active house making and the time spent involved in these activities in a typical week. The current national UK agreement is that CHART will be completed at 1, 2 and 5 years post spinal cord injury and recorded in the national database.

### **NHS England Clinical Reference Group for Spinal Cord Injury (since merged with spinal services CRG)**

The CRG five year plan to 2019 (unpublished) includes the ambition that *'the rehabilitation process will be managed by the service to the point where patients realise their potential to return to occupation, training or employment, engagement and participation of everyday activities'*. It points out that *'Return to work and education/training lag behind continental services. Patients suffer failure of social integration. Quality may be substantially improved'*

### **National Spinal Cord Injury Pathways**

The need for post-discharge vocational support with spinal cord injury specialist rehabilitation (in addition to inpatient support) is referenced within the National Spinal Cord Injury Pathways. The Community Support and Outreach Pathway identifies that the SCI Centre is responsible for: *'Identification of key problems/needs requiring intervention/treatment/further rehabilitation/staff training. Identification of support required for Employment, Vocational Training, Education, Occupation and liaison with relevant agencies and organisations'* (NHS England, 2014). How employment is being addressed according to the pathway in the community may vary between spinal cord injury centres. Each centre has established teams dealing with post-discharge/outpatient support depending upon needs within their own locality. Vocational needs should therefore be assessed as part of the planning of this service.

### **Children and young people with spinal cord injury**

It is important that children and their families, from the earliest stages after injury and even at the youngest ages, are helped to understand their future potential for a fulfilling career no matter what kind of spinal cord injury they have. Education is particularly important for the long-term prospects of children with a spinal cord injury (Anderson & Vogel, 2002) and helps determine their future participation prospects; however if the child, family and school have no idea of the child's current or future potential then their whole education process may be limited by this. Peer role models – children, young people and young adults with a spinal cord injury, can be a powerful way of giving them a vision for what the future may hold for their child, and the expectations/aspirations of the family will be a crucial enabler for the child throughout their childhood. Specialist paediatric spinal cord injury rehabilitation teams work with schools, as will Back Up's schools inclusion service and Back Up's inclusion toolkit provides guidance.

All children should have access to careers guidance from Year 8 (aged 12-13) onwards (Department for Education, 2017) and children with spinal cord injury are no exception. Specialist input from the spinal cord injury centre and specialist voluntary services such as the Back Up Schools inclusion service should be included to support those involved to understand the potential of the young person and how barriers to participation can be overcome.

## 3. What works?

### 3.1 Overarching principles

#### Provision of an effective vocational rehabilitation service

Evidence shows that effective vocational rehabilitation depends on:

- A. Healthcare which includes a focus on work (incorporating the idea of vocational rehabilitation, early intervention, and intervention tailored to individual needs); and
- B. Workplaces that are accommodating (incorporating a proactive approach to supporting return-to-work, and the provision of modified work and accommodations).

Both are necessary; they are interdependent. To make a real and lasting difference, both need to be addressed and coordinated (Waddell, Burton & Kendall, 2008). The first requires integration of vocational goals into the whole rehabilitation process, involving a multidisciplinary approach from the start and through beyond discharge. The second item requires specialist input from the occupational therapy service and partnership working with (potential) employers.

Assessing need and tracking outcomes is key to getting funding as well as understanding and improving services. The Middlesbrough example on page 6 highlights that research and insight into their local need helped get the funding for the post-discharge support therapist which was key to transforming their vocational rehabilitation provision.

#### Early intervention

Evidence consistently shows that early intervention is key across all sectors and patient groups in vocational rehabilitation. The concept of (vocational) rehabilitation after the conclusion of medical treatment is now thought to be outdated and often harmful (Frank, 2016).

In spinal cord injury in the UK specifically, Kennedy (2015) found a consistency between employment intentions measured during rehabilitation and actual community surveys of a similar cohort post-discharge. That is, those who do not have positive intentions to return to work during rehabilitation, generally don't end up doing so. *'In order to improve the proportion of individuals who return to work after their injury, the authors recommend that rehabilitative staff address return-to-work issues earlier in the rehabilitation process, encourage patients to maintain active links with their pre-injury employers, emphasise the wide-ranging benefits of returning to work on both physical and mental health, as well as financial independence, and explore the provision of on-site employment/careers advisory services.'*

### Case study example: quick wins with earlier intervention

The Yorkshire Regional Spinal Injuries Centre realised the importance of early intervention and so opened up their vocational clinics to inpatients as well as outpatients – straightaway they were able to give examples such as one gentleman who as a result of the problem solving at the clinic started to believe that work was possible for him, and felt much more positive as a result. This person otherwise probably wouldn't have turned up to a clinic after leaving hospital. A simple, quick win which made a real difference.

## Leadership for vocational rehabilitation

A **named lead for vocational rehabilitation** is strongly recommended. The role of this lead would be to **coordinate multidisciplinary efforts** around vocational rehabilitation, not to be the sole person thinking about the topic. This person might be an occupational therapist or another suitable rehabilitation professional and whatever their background should be following the Vocational Rehabilitation Association's Standards of Practice. They should be given **specialist training** and a **level of authority** that matches their level of responsibility. To make vocational rehabilitation workable and sustainable, it should be incorporated as a fundamental element into **existing structures and systems** e.g. multidisciplinary meetings / goal planning / patient and family education / discharge planning / outpatient support / referrals to other agencies and peer support organisations.

## Person centred approach and ongoing support

Different people take different lengths of time for their return to work journey and hence ongoing therapeutic support post-discharge is critical. Many spinal cord injury centres report that the majority of their patients are not ready to progress work issues until discharged from hospital. Establishment of the outreach liaison occupational therapist post at Middlesbrough is one example of how they enabled these issues to be addressed and improved return to work rates.

It is therefore important to aim to discharge people from inpatient rehabilitation with:

- a belief/understanding that work is possible and can be beneficial
- a plan of action in place to work towards that, being actively connected with proactive sources of support and help along the way.

## Beliefs around returning to work are central to adjustment, coping and inclusion

Positive expectations regarding resumption of work after SCI are an important indicator of successful reintegration in work (Schonherr et al 2004). The whole staff team in contact with the patient and their family, from day one after a spinal cord injury, can and do play a role in shaping those expectations. See section 3.2 for more details.

Bio-psycho-social factors often aggravate and perpetuate disability. They may also act as barriers to recovery and return to work. Occupational therapists are well placed to help patients identify and problem-solve the bio-psycho-social factors around a person's return to work.

On the psychosocial aspects, how people think and feel about their health problems help to determine how they deal with them and their impact. There is extensive clinical evidence that beliefs aggravate and perpetuate illness and disability (Main, Sullivan & Watson, 2012; Turk & Gatchell, 2002). Beliefs influence perceptions and expectations; emotions and coping strategies; motivation and uncertainty. Beliefs can be challenged by experts but also particularly powerfully by trained peer supporters.

Much is known about how people adjust to and cope with life after a spinal cord injury. To help people to cope successfully we need to help them to see going back to work as a 'manageable challenge' (Duff and Kennedy 2003); something which they do have the ability to achieve; with some adjustments and with help to break down the goals towards that.

The beliefs of others (employers / family and friends) and the need for adjustments on their side are also critical. Environmental and social factors are among the main barriers to employment (Murphy et al, 2011). Discrimination and inaccessibility at the workplace are highly important negative factors for employment (Escorpizo et al, 2014). Occupational therapists are well placed to help identify barriers, working with all stakeholders, advocate on behalf of the patient, and support them to navigate and overcome barriers whilst staying positive and focussed as much as possible. Vocational rehabilitation specialists in voluntary organisations and peer supporters, mentors and advocates can also play an important role.

The Equality and Human Rights Commission (2017) indicate that the employment gap between disabled people and non-disabled people has widened in the last 6 years. Put into the national context, it may be no wonder that employment rates

post spinal cord injury have also fallen. Much of that stems from discrimination – both indirect and direct – and so any work to challenge patients' self-belief has to go hand in hand with support to challenge the perception and actions of third-parties too.

**Commissioners and managers should therefore ensure that, in summary:**

1. The level of need has been assessed (numbers of patients of working age or transitioning towards working age, employment status and return to work rates)
2. A named lead has been appointed to coordinate the multidisciplinary approach to vocational rehabilitation (within the spinal cord injury centre and working with outside agencies). This person should be trained and given appropriate authority. They will:
  - coordinate efforts to ensure that ALL staff are aware of their role in relation to vocational rehabilitation and shaping people's goals and expectations
  - work collaboratively to ensure vocational goals are incorporated into goal planning and discharge planning systems and processes during and beyond discharge
3. Vocational rehabilitation is integral from day one and beyond discharge. By discharge the aim should be that the patient and their family (and employer / potential employer):
  - have every chance of believing that work is possible and can be beneficial
  - are linked into proactive, ongoing support beyond discharge to help them to achieve this goal, both from the spinal cord injury centre and from other sources such as local agencies and spinal cord injury charities
4. Vocational rehabilitation should involve support for challenging beliefs of significant others such as family, friends and (potential) employers as needed
5. Vocational outcomes should be tracked beyond discharge

## 3.2 The vital role of all staff involved, even from day one

### People make very early judgments

Insight findings show that **people make very early decisions and judgements around work** after injury/illness (Greater Manchester Public Health Network, 2013, unpublished; see University of Salford, 2015). This was corroborated by a study at Stoke Mandeville (Kennedy, 2015) which found that people's expectations and plans around returning to work during inpatient rehabilitation were highly predictive of actual outcomes.

However, many healthcare practitioners often avoid starting the conversation and do not routinely address work issues (Moore, 2011). **Attitudes and beliefs of practitioners** (about work) can **significantly influence patient decisions** (Wade and Halligan, 2004) and outcomes of rehabilitation (Bishop et al, 2008). These findings reflect feedback from many staff in UK spinal cord injury centres when researching these guidelines. This highlights the **importance of raising awareness amongst all staff** who come into contact with the injured person and family – from day one – even in the acute stages.

### Early and empowering conversations with person and family

It is therefore important to make all staff involved with someone with a spinal cord injury and their families, even at the acute stage, aware of the importance of early and empowering discussions around work. **Staff need a basic understanding that work is possible and can be highly beneficial** for physical and mental health, social interaction and participation, self-esteem and a sense of purpose.

Any staff member around a person with an injury, from day one, can contribute to positive expectations around work. Even if the person is not ready to make plans yet, informal conversations all play an important role in shaping perceptions. Conversely, any staff member could inadvertently negatively affect their or their family's beliefs about, and attitudes to, work through well-meaning but misguided comments.

Talking about work in broad terms during early stages could indeed facilitate adjustment in general because it **sets out the expectation** that spinal cord injury is something that is a "manageable challenge", something that can be successfully negotiated and incorporated into someone's life, and therefore subtly challenges the more negative cognitive predictions (Duff and Kennedy, 2003).

Initial discussions about work need to take place at the earliest stages. These may be limited to identification of the nature of any employment, advice to remain in contact with their employer and reassurance that there are many ways to support workers back into employment (Frank, 2016). All staff can and should reinforce these messages.

So by:

- not avoiding the topic; avoiding vague or over-protective language
- having **positive expectations and ambition and facilitating aspirations**
- being prepared to challenge unhelpful assumptions – "what makes you think that?" "when did you decide that work isn't an option for you?"
- being able to **signpost/refer to specialist support** at an early stage,

...we can all make a huge difference.

## 3.3 Guidance for occupational therapy services in spinal rehabilitation

### Staffing and skills

**All qualified occupational therapists have relevant core skills and can access relevant guidance** to assess barriers to working, agree vocational goals in partnership with the patient and multidisciplinary team, and support people through overcoming barriers. However, it is common in many hospitals that the increasing focus on discharging people more rapidly has moved many occupational therapists away from their core focus on vocational rehabilitation.

The Royal College of Occupational Therapists (RCOT) believes that any qualified occupational therapist should be prepared to apply their skills to vocational rehabilitation. Even without previous experience or specific qualifications in this type of work, occupational therapists can still make a substantial contribution to the resolution of functional difficulties in the workplace. The use of available guidance and reflective practice will enable the development of vocational rehabilitation skills through experience. The RCOT's Work Matters booklet (2007) might be a helpful place to start.

Sheppard and Frost (2016) stated that vocational rehabilitation is becoming an increasingly common area for occupational therapists, helping people to identify physical, social and psychological strengths and potential barriers to resuming work, and crucially, strategies to address these barriers. Ross (2007, p.10) described how occupational therapists 'may act as a bridge between employers, doctors, clients and others involved in the vocational rehabilitation process'.

Motivational interviewing skills are well established in the field of vocational rehabilitation and can be very helpful in working with people who may have ambivalent feelings about work.

As mentioned in section 3.1, a **named lead for vocational rehabilitation** is strongly recommended. The role of this lead would be to **coordinate multidisciplinary efforts** around vocational rehabilitation, not to be the sole person thinking about the topic. This person might be an occupational therapist or another suitable rehabilitation professional. They should be given **specialist training** and a **level of authority** that matches their level of responsibility.

The Royal College of Occupational Therapists specialist work section and the Vocational Rehabilitation Association both provide guidance and networking opportunities. Examples (not recommendations) of training providers include Sheffield Hallam University, University of Salford, and the International Disability Management Standards Council).

### Assessing needs and tracking outcomes

**Assessing need and tracking outcomes, for individuals and for the whole patient group, is key to planning, resourcing, understanding and improving services.** As demonstrated by the Middlesbrough example (section 2.2), such research data helped secure funding for the post-discharge occupational therapist who more than doubled return to work rates.

There are currently no specific standardised assessment tools or outcome measures specifically for vocational rehabilitation in spinal cord injury; however, as part of NHS England's Care Pathways (NHS England, 2014), the current national UK agreement is that the CHART participation measure (which includes employment) will be completed at 1, 2 and 5 years post spinal cord injury and recorded in the national database. The CARF international accreditation scheme for rehabilitation places enormous importance on these longer term measures in order to assess 'durability' of outcomes.

The following further tools / measures may be of interest:

- The ICF Core Sets for vocational rehabilitation and the WORQ (work rehabilitation questionnaire) (Hostettler, 2017)
- Vocational Navigation from Bramley (2005)
- The Canadian model of occupational performance (COPM) (Law et al, 1990)
- The model of human occupation (MOHO) (Taylor, 2017)
- Workplace assessment tools – from Holmes (2007)

## Case study example:

The National Rehabilitation Hospital in Dublin offer all their spinal cord injury patients a vocational assessment during rehabilitation, of which just under 73 % take up the opportunity prior to discharge. This links them in with ongoing support up until they take up work or request no further contact

### Early and continuing intervention

There is extensive and consistent evidence that early multidisciplinary interventions encourage and increase the effectiveness of return to work (Waddell et al 2008, Kennedy 2015). Staff in the acute stage need to have an awareness of vocation. Vocation should be discussed prior to the first goal planning, at least to identify the nature of any employment, advise to remain in contact with the employer (if applicable) and to reassure that there are many ways to support workers back into employment (Frank, 2016). . The multidisciplinary team should certainly fully consider vocational goals from the start of the rehabilitation process and proactively follow these up.

### A person-centred approach; coaching and motivational interviewing

Employing a person-centred approach will help to ensure that individual differences in readiness for the work conversation can be accounted for. This requires flexibility and interpersonal skills:

...from sowing seeds – ‘it’s ok to ask’,

...to respectfully challenging unhelpful assumptions/misconceptions – ‘what makes you think that?’, ‘What kind of work can’t you do/is unsuitable for you?’ ‘What jobs do not require being on your feet all day?’

...to communicating positive expectations of the person and fostering a self-management and problem solving approach through coaching and motivational interviewing approaches – ‘list your abilities/skills’; ‘what makes you unique’; ‘what are you good at?’; ‘what are your interests?’; ‘what makes work important?’; ‘you have xxx health limitations...make a list as to what you CAN do?’; ‘where would you like to be in 5-10 years’ time?’; ‘what could you do right now to help you move closer to your career goals?’

### Partnership working

Collaboration is critical within the multidisciplinary spinal cord injury team and with peer support organisations, local health and care services and employers, as well as with the Department of Work and Pensions services and statutory careers/skills development services, who may also be gatekeepers to Access to Work funding.

Where co-morbidities exist, it is highly desirable to work with local or national specialised organisations and services where they exist. For example there are examples of longstanding effective return to work programmes for people following acquired brain injury in some areas.

## Case study example:

The Community Head Injury Service in Buckinghamshire have a well established vocational rehabilitation service for people with acquired brain injury in the area <http://www.buckshealthcare.nhs.uk/Our%20clinical%20services/A%20to%20Z%20of%20clinical%20services/chis.htm>

### Proactive post discharge support

It is recommended that all spinal cord injury centres seek to resource proactive vocational support beyond discharge in a way which meets the needs of their local population. In any case, support from charities and other organisations is available and it is



recommended that the individual is actively referred to external organisations and agencies to enable them to pursue vocational opportunities following discharge. External organisations such as the Spinal Injuries Association and Back Up provide return to work courses and proactive ongoing vocational support upon discharge. **Referrals are to be encouraged but do not absolve responsibility** for vocational goals. Collaboration should enhance rather than replace the process.

By the time the person is discharged, they may not yet be ready to make concrete plans but the aim should be that they should at least be at the point where they are ready to accept that work can be both possible and beneficial, and be linked into an ongoing proactive network of support to help maintain the focus on work.

### The role of vocational navigator and some guidance as to what might be involved

The Royal College of Occupational Therapists clarifies the occupational therapy role in *Work Matters: Vocational Navigation for Occupational Therapy Staff* (College of Occupational Therapists et al, 2007). This guides staff in empowering individuals and suggests approaches to create effective partnerships for collaborative working.

The vocational navigator role ensures a consistent approach by all the occupational therapy team.

*'Taking on the role of navigator involves co-working, collaboration, mutual understanding and establishing a shared vision about a destination and the route needed to achieve it. This requires networking, acquiring information, providing practical support, and knowing some of the short cuts and diversions. The map varies with each individual so the navigator, or occupational therapist, must have the courage to acknowledge what they don't know or when they are lost, and to ask others for directions'* (Bramley 2005)

The navigator will adopt the bio-psycho-social approach to work with the injured person to assess the context of the disability, identifying precise barriers to the return to / journey into work. Tailored, supportive interventions can then be planned together with the patient.

Commonly, a hierarchy of return to work goals is considered – the items higher up the list will be most effective at resulting in a quicker / easier return to work (and don't prevent choices being made at a later date to progress to other goals):

1. Same job, same employer
2. Different job, same employer
3. Same job, different employer
4. Different job, different employer (Frank, 2016 gives a wider, more detailed options list)

Ongoing support and review is vital to stay focused on vocational goals and may include:

- Introducing activities relevant to the skills and abilities required to return to work
- Increasing participation in activities
- Supporting development of coping strategies to anticipate and manage actual and potential barriers and for day to day living
- Shifting behaviours and beliefs to increase confidence (in the injured person but also considering family, friends, colleagues)
- Re-establishing work related routines (work can be seen as part of rehabilitation rather than necessarily the endpoint)
- Recommendations on access, adaptations and equipment
- Maintaining contact and/or relationships with the workplace (where feasible and appropriate). Worksite visits as required
- Workplace modifications (reasonable adjustments) that reduce disability and disadvantage; and enable productivity, participation and job satisfaction, for example:
  - o The use of assistive technology
  - o Ergonomic re-design of work / work environment
  - o Education of employers / colleagues
- Consideration of other factors such as funding for equipment or adaptations, the level of care, employment history and psychosocial issues (Ottomanelli & Lind, 2009). Liaison with Access to Work, community services and voluntary sector organisations to maximise opportunities and minimise barriers. Communication and coordination with employers and other



healthcare professionals in the community to ensure effective and a smooth transition (Waddell et al 2008).

- Supporting work retention: maintaining a dialogue post discharge with patients who have returned to work. Spinal cord injury centres offer patients the opportunity to attend regular reviews post discharge. It is highly recommended to include in the review, discussion around productivity; to identify factors which may be influencing or affecting a patient's choice to stay in work. Early identification of issues would enable planned interventions, strategies and support to be put in to place prior to employment breakdown. A multidisciplinary approach, identifying key persons, with a clear identified pathway of responsibility would be required to ensure action happen post review.
- Consideration of secondary health complications. Employment after spinal cord injury is associated with lower health complications (Marti et al 2016). Supporting people to prevent or swiftly manage secondary complications such as pressure sores and UTIs is important, in particular to prevent the disruption to work of hospitalisation (Meade et al, 2011). Supporting people to manage chronic pain is a key goal. People with unmanaged pain are less likely to sustain employment (Meade et al, 2011) and pain may be a particular barrier to work for older adults (Marti et al 2016). Pain can stop people being active and yet keeping busy and socially connected is a helpful coping strategy (Raichle et al. 2007)

### Integration of vocational rehabilitation into the whole

Staff we spoke to who were working in isolation in their settings were struggling (for example setting up a vocational clinic for outpatients that no one turned up to, but not asking about work as routine in outpatient appointments). Working in isolation is stressful for staff and more likely to be ineffective. Building vocational rehabilitation into goal-setting, clinics and reviews for all patients, not treating it as a separate add-on, will make it more workable and affordable, as well as helping to reinforce the idea that returning to work is regarded as 'the norm'.

### Further resources

The British Society of Rehabilitation Medicine's **guidelines on Vocational Assessment and Rehabilitation for people with Long-Term Neurological Conditions** (2010)

The Vocational Rehabilitation Association's **Standards of Practice** (2013)

The book 'What Colour is your Parachute' (Bolles, 2017) has been recommended by some in the sector as a useful resource for those who need to consider changing career

Legislation, government drivers and further guidance

- **Health, Work and Wellbeing evidence and research** from UK Government (DWP)
- **Guidance from the Health and Safety Executive** for disabled people and their employers around how health and safety legislation should not be used to justify discrimination (HSE)
- **Equality Act 2010 guidance** from UK government (GEO / EHRC) and the **Disability Discrimination (Northern Ireland) Order 2006** from UK government (National Archives)
- **Department for Work and Pensions (DWP) website** – includes guidance around employment and disability. For Scotland see also **Equality in Scotland: Disabled People** (Local Government and Communities Directorate). For Northern Ireland see also **Employment Support Information** from nidirect.

Key organisations

- Royal College of Occupational Therapists <https://www.rcot.co.uk/about-us/specialist-sections/work-rcot-ss>
- Vocational Rehabilitation Association <https://vrassociationuk.com/>
- User organisations especially [www.backuptrust.org.uk](http://www.backuptrust.org.uk), [www.spinal.co.uk](http://www.spinal.co.uk), [www.aspire.org.uk](http://www.aspire.org.uk) and [www.spinalinjuries.ie](http://www.spinalinjuries.ie) with dedicated vocational services
- Further national, central and local support may be available to help with the delivery of different aspects of vocational rehabilitation to people with a spinal cord injury. Some of the organisations and websites are detailed in the Appendix, but given the huge scope of vocational rehabilitation this list isn't exhaustive.

## 3.4 The vital role of peer support

### High impact

Peer-led support is **well established in spinal cord injury rehabilitation as having a vital role** to play, and vocational rehabilitation is no exception. Peer support involves people drawing on shared personal experience to provide knowledge, social interaction, emotional assistance or practical help to each other, often in a way that is mutually beneficial (Nesta / National Voices, 2015). NHS England's Five Year Forward View referred to Peer Support as one of the '**slow burn, high impact**' interventions that should be seen as 'essential' to the future of the NHS.

### Able to challenge beliefs and lead to better outcomes

People's beliefs about what's possible and desirable for them are critical. Peers can often most successfully challenge people's beliefs, expectations and behaviours, as they can be seen as more credible and more understanding to the user than others who haven't personally experienced the situation they are in. They can also be a living embodiment of what is possible. Peer support has been evidenced to have the potential to **improve the experience, psycho-social outcomes, behaviour, health outcomes and service use** amongst people with long-term physical and mental health conditions. It's also been found to be most effective for improving health outcomes when facilitated by trained peers. Peer support works well when delivered face-to-face, by telephone or online (Nesta / National Voices, 2015).

In spinal cord injury specifically, peer mentoring experience has been shown to be related to higher occupational activity and higher life satisfaction in the long term (Sherman, DeVinney & Sperling 2004).

Peer support may take a range of forms: four are evidenced to be most effective (Nesta / National Voices, 2015):

- face-to-face groups run by trained peers which focus on emotional support, sharing experiences, practical activities and education
- one-to-one support offered face-to-face or by telephone
- online forums, particularly for improving knowledge and anxiety
- support offered regularly (such as weekly) for three to six months

Training is key for peer supporters as well as role clarity, boundaries, support and structures that protect both the giver and recipient of support. With these in place, the support can benefit both parties immensely.

### Integral part of the team

Vocational rehabilitation should therefore be seen as a collaborative approach between peer support organisations and health professionals with the injured person and their family, school, workplace, etc. Again, early intervention to regard returning to work as the 'norm' and an achievable goal is vital and would involve a joined-up approach by all involved in rehabilitation to reinforce this positive message.

Peer mentoring for family members may additionally be able to play a role in raising expectations amongst the injured person's close network.

It is worth considering that, in relation to vocational goals, a peer for the injured person may not necessarily always have a spinal cord injury themselves; it may be someone with relevant work experience and/or contacts. It is worth supporting people to think through their networks to explore who can help.

## 3.5 The role of solicitors and case managers where there is a claim

A significant minority of people with spinal cord injuries have legal claims in relation to their injury, particularly with road traffic incidents and sometime medical negligence cases. **The claims process is often seen as a huge barrier to getting people back to work but in fact should be the opposite – a facilitator** of the journey (back) into work. Increasing awareness of this amongst rehabilitation staff, patients and families can only be helpful.

If a person sustains a spinal cord injury and is able to establish that somebody else was at fault then they will have a potential claim to recover compensation, if the other person's negligence caused the injury. With spinal cord injuries, the most common types of claims arise from incidents on the roads, or medical negligence. Once liability is established (often relatively straightforwardly in road traffic collisions; medical negligence often takes a lot longer) **a claimant can gain access to interim payments of compensation. This will enable them to set up a rehabilitation programme which should include support for vocational rehabilitation at the earliest opportunity**, prior to any final settlement of their claim. So long as any rehabilitation programme is recommended by an appropriately qualified person, then the cost of such a programme should be recoverable (and doesn't require reliance on state provision even if the alternative is expensive).

**Solicitors' responsibilities are clear and there is consensus in the sector, represented by the Rehabilitation Code and attached guidance for case managers as well as the Guide to the Conduct of Cases involving Serious Injuries:**

Lawyers representing injured people are required to consider other issues apart from maximising compensation. The **Rehabilitation Code** (IUA, 2015) has been agreed by all stakeholders such as the Association of Personal Injury Lawyers (APIL) and the Association of British Insurers (ABI) and describes the obligation of the Claimant's solicitor:

*'The Claimant's solicitor's obligation to act in the best interest of their client extends beyond securing reasonable financial compensation, vital as that might be. Their duty also includes considering, as soon as practicable, whether additional medical or rehabilitative intervention would include the claimants present and / or longer term physical and mental wellbeing. In doing so there should be full consultant with the Claimant and / or the family and any treating practitioner where doing so is proportionate and reasonable. This duty continues throughout the life of the case, but is most important in the early stages.'*

This would include vocational rehabilitation. Vocational rehabilitation is specifically mentioned in '**A Guide for Case Managers and Those Who Commission them**' (CMS UK, 2015) which is attached to the Rehabilitation Code. This requires case managers to consider the possibility of vocational rehabilitation at the earliest appropriate moment. This should involve dialogue with employers. It also encourages case managers to involve an individual with suitable expertise if they don't have expertise in vocational rehabilitation.

Perhaps most significant is the agreement of the **Guide to the Conduct of Cases involving Serious Injuries** (APIL et al, 2015). It is another agreement between the key stakeholders in personal injury claims; APIL, ABI, the Federation of Insurance Lawyers (FOIL). This Guide is aimed at cases with a potential value in excess of £250,000 (which would include all spinal cord injury cases). Here, a discussion is required at the earliest opportunity by all parties to consider effective rehabilitation where reasonably required. The approach is to try and agree an appropriately qualified case manager. Whilst this Guide does not make specific reference to vocational rehabilitation, it is tacit that this would be a consideration in every case. It follows from this **that in every single case where liability is established, rehabilitation will be a priority consideration and that will include vocational rehabilitation. There is no reason why the injured person's solicitors should not have secured sufficient funds to put an effective package in place.**

Thirty-five firms of solicitors have signed up to the Serious Injuries Guide, including all the leading personal injury firms. A number of insurance companies (representing about 85 % of the insurance industry) have also signed this agreement. However there isn't currently a similar arrangement in place with the NHS Litigation Authority.

Assuming the injured person is fit to return to some form of work, **they should not be advised by their lawyer that they should not work, for the purpose of maximising their claim.** In any event, an individual is required, as a matter of law, to mitigate their loss. This means that if work is available to them, and it is reasonable for them to accept this, then they may be penalised in respect of the amount they recover if they do not take this job opportunity.

Regardless of whether a person has in fact been advised not to work by a solicitor, healthcare and support practitioners should in any case be confident, steadfast and determined in their advice, support and aspirations for the individual concerned. This might involve explaining the long-term, holistic benefits of work and encouraging the person to at least ask about a vocational support package as part of the claim.

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## Sources of Vocational Rehabilitation Support & Advice

There is national, central and local support available to help with the delivery of different aspects of vocational rehabilitation to people with a spinal injury. Some of the organisations and websites are detailed below, but given the huge scope of Vocational Rehabilitation this list isn't designed to be exhaustive. Aside from there being other central organisations than can offer vocational guidance, it also doesn't allow for 'local knowledge' or indeed support linked to specific Spinal Centres (for example SPINE [www.spine-pinderfields.org.uk](http://www.spine-pinderfields.org.uk) at Pinderfields Spinal Centre or SSIT [www.ssit.org.uk](http://www.ssit.org.uk) at Salisbury).

### Spinal Injury Charities

Aspire	<a href="http://www.aspire.org.uk">www.aspire.org.uk</a>
Back Up	<a href="http://www.backuptrust.org.uk">www.backuptrust.org.uk</a>
Cauda Equina Society	<a href="http://www.caudaequinauk.com">www.caudaequinauk.com</a>
Regain	<a href="http://www.regainsportscharity.com">www.regainsportscharity.com</a>
Spinal Injuries Scotland	<a href="http://www.sisonline.org">www.sisonline.org</a>
Spinal Injuries Association	<a href="http://www.spinal.co.uk">www.spinal.co.uk</a>
Transverse Myelitis Society	<a href="http://www.myelitis.org.uk/">www.myelitis.org.uk/</a>
WheelPower	<a href="http://www.wheelpower.org.uk">www.wheelpower.org.uk</a>

[The equivalent support charity in the Republic of Ireland is SII (Spinal Injuries Ireland) [www.spinalinjuries.ie](http://www.spinalinjuries.ie) ]

### Central & Local Government

UK Government	<a href="http://www.gov.uk">www.gov.uk</a>
Access to Work	<a href="http://www.gov.uk/access-to-work">www.gov.uk/access-to-work</a>
Careers Service Northern Ireland	<a href="http://www.nidirect.gov.uk">www.nidirect.gov.uk</a>
Careers Wales	<a href="http://www.careerswales.com">www.careerswales.com</a>
National Apprenticeships Service	<a href="http://www.apprenticeships.gov.uk">www.apprenticeships.gov.uk</a>
National Careers Service	<a href="http://www.nationalcareersservice.direct.gov.uk">www.nationalcareersservice.direct.gov.uk</a>
Skills Development Scotland	<a href="http://www.skillsdevelopmentscotland.co.uk">www.skillsdevelopmentscotland.co.uk</a>

### National Organisations

Association for Disabled Professionals	<a href="http://www.adp.org.uk">www.adp.org.uk</a>
Business Disability Forum	<a href="http://www.businessdisabilityforum.org.uk">www.businessdisabilityforum.org.uk</a>
Citizens Advice Bureau	<a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a>
Disability Rights UK	<a href="http://www.disabilityrightsuk.org">www.disabilityrightsuk.org</a>
Equality & Human Rights Commission	<a href="http://www.equalityhumanrights.com">www.equalityhumanrights.com</a>
Evenbreak	<a href="http://www.evenbreak.co.uk">www.evenbreak.co.uk</a>
Great with Disability	<a href="http://www.greatwithdisability.com">www.greatwithdisability.com</a>
Prince's Trust	<a href="http://www.princes-trust.org.uk">www.princes-trust.org.uk</a>
Remploy	<a href="http://www.remploy.co.uk">www.remploy.co.uk</a>
Shaw Trust	<a href="http://www.shaw-trust.org.uk">www.shaw-trust.org.uk</a>
Open University	<a href="http://www.open.ac.uk">www.open.ac.uk</a>

## **Self-Employment**

Disabled Entrepreneurs  
Start Your Own Business

[www.disabledentrepreneurs.co.uk](http://www.disabledentrepreneurs.co.uk)  
[www.syob.net](http://www.syob.net)

## **Volunteering**

Do-It  
National Council for Voluntary Organisations  
Voluntary Worker

[www.do-it.org.uk](http://www.do-it.org.uk)  
[www.ncvo.org.uk/ncvo-volunteering](http://www.ncvo.org.uk/ncvo-volunteering)  
[www.voluntaryworker.co.uk](http://www.voluntaryworker.co.uk)