

**NATIONAL CANCER SURVIVORSHIP INITIATIVE
WORK AND FINANCE WORKSTREAM**

**EVALUATION OF THE VOCATIONAL REHABILITATION PILOT PROJECTS:
EARLY FINDINGS – SEPTEMBER 2010**

EXECUTIVE SUMMARY

People with cancer experience significant difficulties with regard to employment. The vocational rehabilitation support available to people with general health conditions (such as musculo-skeletal disorders) is neither accessible to, nor entirely appropriate for, people with a cancer diagnosis. To address this, the National Cancer Survivorship Initiative has funded seven pilot sites across England to test a four-level model of vocational rehabilitation for people with cancer. An evaluation of these seven pilot sites is underway, to identify the benefits and costs of vocational rehabilitation for people with cancer. This report sets out the initial findings emerging out of the early work of the pilot sites. Through interviews and observations with service providers and service users, five emerging themes have been identified:

1. Patients want attention to be paid to work issues at an early stage in their illness, and then revisited during the course of treatment and follow-up.
2. Health professionals inadvertently give patients mixed messages about work.
3. Line managers are a key point of contact between patients and employers, and do not necessarily have the knowledge and skill to manage a patient's return to work effectively.
4. Patients are not generally knowledgeable about their rights and responsibilities with regard to employment.
5. Specialist vocational rehabilitation services can predict and pre-empt problems that patients might not (yet) be aware of.

These findings highlight the essential role that health professionals play in recognising and responding appropriately to the work problems arising as a consequence of a diagnosis of cancer. In addition to direct support provided to patients experiencing employment difficulties, specialist vocational rehabilitation services can provide valuable education and support to front-line health professionals and employers.

INTRODUCTION

Cancer has a serious and significant impact on a person's ability to work, with consequences for economic self-sufficiency, as well as for an individual's sense of identity, self worth and quality of life.

There are over 700,000 people of working age who have had a diagnosis of cancer in the UK.¹ Each year 109,000 people of working age are diagnosed with cancer. More than 90% of cancer patients' households suffer a loss of income and/or increased costs as a direct result of cancer.² Many people who have had cancer treatment want to go back to work when they feel fit and ready.^{3,4} However, evidence suggests that some are unable to return to work after a cancer diagnosis: cancer survivors are 1.4 times more likely to be unemployed than people who have not had cancer.⁵

The support received by people with cancer in relation to work has been shown to be inadequate. Cancer survivors are not routinely given advice from their doctors about the impact of cancer on work, with less than 40% of people being advised by health professionals about the impact cancer treatment may have on their ability to work. Employers are often not providing advice either; 47% of people who informed their employer of their diagnosis did not have sick pay entitlement, flexible working conditions or work place adjustments discussed with them by their employer.⁶ Currently available schemes to support people with health conditions to return to work are limited in their accessibility and their ability to meet the needs of people with cancer.⁷

To address these issues, the National Cancer Survivorship Initiative (NCSI)⁸ has funded seven pilot projects, spread across England, to test a four-level model of vocational rehabilitation for people with cancer (see Fig. 1).⁹

Vocational rehabilitation

Vocational rehabilitation is defined as *'whatever helps someone with a health problem to stay at, return to and remain in work'*: it is an idea and an approach as much as an intervention or a service'.¹⁰

While research on the vocational rehabilitation needs of people diagnosed with cancer is limited, there is a strong scientific evidence base for many aspects of vocational rehabilitation in commonly occurring health conditions such as musculoskeletal disorders, mental health problems and cardio-respiratory illnesses.¹⁰ While many of the strategies effective in vocational rehabilitation services for other health conditions are likely also to apply to people with cancer – facilitating partnerships between health services and employment support, and promoting early intervention¹¹ – people with cancer have specific and distinctive problems and concerns which need to be taken into account in the development and provision of employment support services. These problems can be physical, emotional and practical, and can arise both from the cancer itself and from the cancer treatment. Jenny, from Cambridgeshire, gives an example: "I felt very tired when I returned to work after chemotherapy. It knocked the stuffing out of me, which was a surprise as I'm normally full of energy. I found this depressing but my employers were very supportive and allowed me lots of leeway with my working hours."¹²

The NCSI vocational rehabilitation model

The NCSI Vocational Rehabilitation model (Fig. 1) has been developed through extensive consultation with cancer patients, clinicians and employers.⁹ It describes four levels of support and information for people with a cancer diagnosis who wish to remain at or return to work. At levels 1 and 2 information is provided, alongside opportunities for face to face discussion and signposting to other sources of support. Levels 3 and 4 provide access to learning programmes and a case manager who will work together with individuals and employers to deliver expert vocational rehabilitation. This may include referrals to specialist services such as physiotherapy. Through the lifetime of the vocational rehabilitation project, this model will be tested and refined on the basis of the experiences of the seven pilot sites.

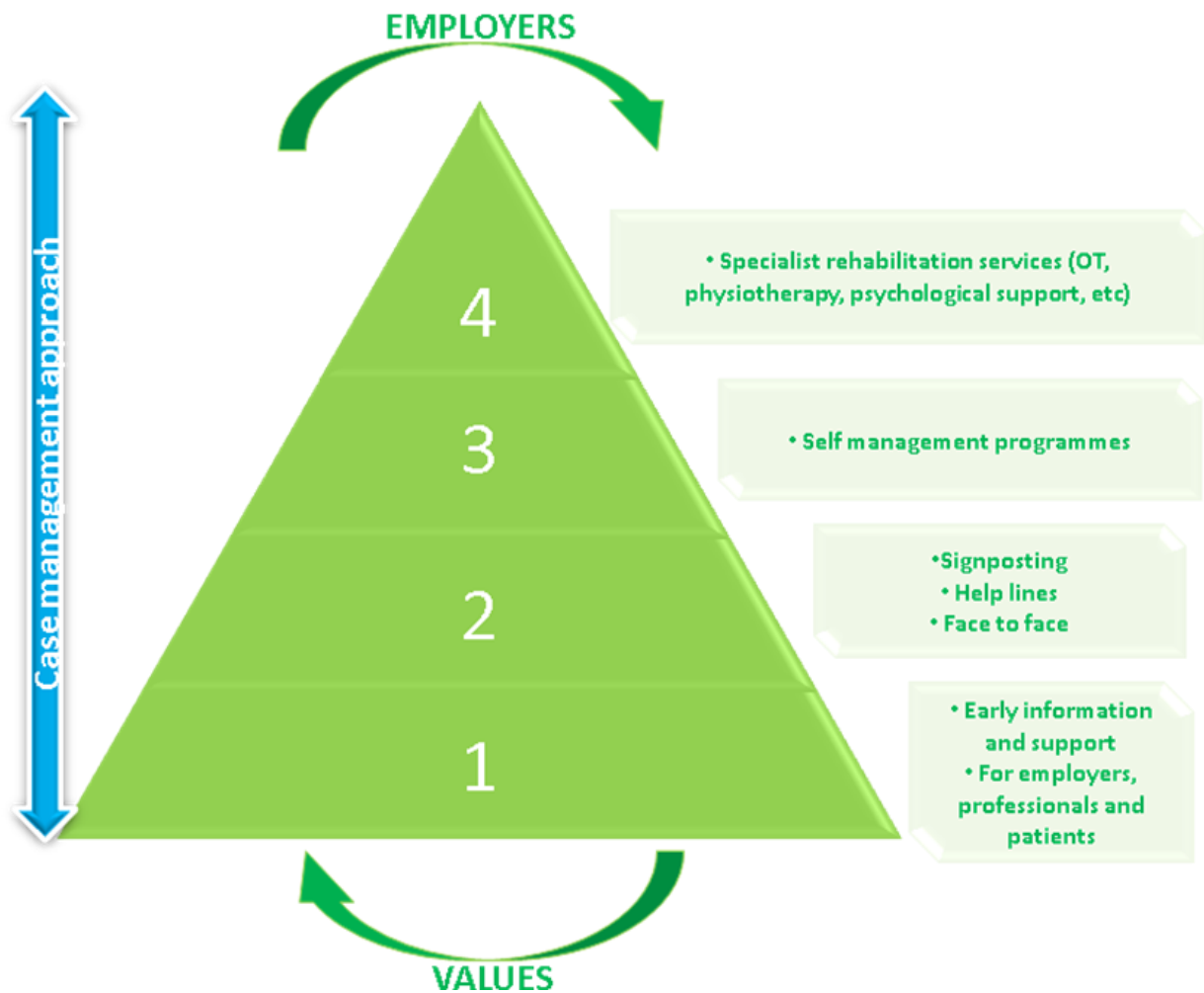


Fig. 1: Proposed four level model of vocational rehabilitation for people with cancer

THE SEVEN PILOT SITES

The seven pilot sites are funded for one year from April 2010. They are partnerships that have been formed to develop existing services in the area of vocational rehabilitation. They are located across England, and represent a range of service providers and configurations, as follows:

The Shaw Trust with the Christie Hospital: Manchester

The Shaw Trust, a vocational rehabilitation charity, is working in partnership with the Christie NHS Foundation Trust, a specialist cancer hospital, to extend the Christie's current rehabilitation service to incorporate vocational rehabilitation. Working closely with the existing occupational therapy and physiotherapy services, a Shaw Trust employment specialist provides written and on-line resources (at level 1) through to expert individualised assessment of work-related problems with full support for patients seeking to remain in or to return to work (at level 4).

Doncaster Community Healthcare: Doncaster

This service is based at St John's Information and Support Centre, which is co-located with St John's Hospice in Doncaster. A case manager (an occupational therapist), physiotherapist, occupational therapist, complementary therapist and support worker have been recruited to work closely with the

Information Facilitator, DIAL and counselling services. They will provide self-management group programmes, specialist fatigue, exercise and breathlessness management group programmes, physiotherapy, individualised and workplace assessments and support.

National Hospital for Neurology and Neurosurgery (NHNN): London

The NHNN is building on an existing vocational rehabilitation service provided for people with multiple sclerosis, and extending this to patients with brain tumours. It is led and provided by occupational therapy and neuropsychology staff. Assessment and interventions are delivered on an out-patient and in-patient basis, and consider mood, cognition and functional abilities in relation to work. Work specific interventions include facilitating graded return to work and symptom management.

NHS Blackburn with Darwen: Lancashire

The Lancashire Condition Management Programme (CMP) is well established and works in close partnership with the four NHS regions in the county, as well as with the 19 Jobcentre Plus offices and a network of providers of employment support. This pilot site uses components of the existing Condition Management Programme to provide an enhanced vocational rehabilitation service for people with cancer. It facilitates their access to the range of resources and services available across the county as well as providing specialist individualised employment support. The service is provided by two experienced CMP specialists, one nurse and one physiotherapist.

NHS South of Tyne and Wear: Gateshead

Similar to the pilot site in Blackburn with Darwen, the service based at NHS South of Tyne and Wear has its roots in a well-established Condition Management Programme, and is delivered by professionals (with nursing, social work and occupational therapy backgrounds) who are experienced CMP service providers. It builds on the strong voluntary and third sector links established through CMP, offering a range of information and support services for people with cancer, as well as an outreach programme to health care professionals to raise awareness of patients' employment-related needs.

Mount Vernon Cancer Network: Hertfordshire

This pilot site will operate across the Mount Vernon Cancer Network, which includes Hertfordshire, South Bedfordshire, and parts of Buckinghamshire, Berkshire and London. It is led by a project manager/vocational rehabilitation champion, working closely with a variety of other professionals across the Network. The role of the champion is to raise awareness of issues around cancer and employment with front line health professionals, draw on existing return to work support services, and improve referral pathways to specialist psychological and rehabilitation services. This pilot is identifying existing levels of workforce knowledge and skills, and mapping the vocational rehabilitation available in the Network in order to support further development of vocational rehabilitation services across the Cancer Network workforce.

Orbitals and the Olive Tree Cancer Support Centre: Crawley and the Gatwick Diamond

This pilot site is a partnership between the Olive Tree Cancer Support Centre based at Crawley Hospital, and Orbitals Ltd, a private consultancy specialising in career development and coaching. In addition to information, signposting and one-to-one coaching, the pilot has a strong focus on engaging and upskilling employers, supported by CADIA, the Gatwick Diamond Employers Association.

THE PROJECT EVALUATION

A project evaluation is being undertaken through the pilot sites in order to develop an understanding of the optimal configuration and delivery of vocational rehabilitation services for people with cancer, and to define which outcomes are of importance to different stakeholders (for example, commissioners, funders, patients, providers, employers).

The evaluation aims to investigate the benefits and costs of vocational rehabilitation for people with cancer. The specific questions addressed are:

1. What are the outcomes of the vocational rehabilitation programmes, and how are these achieved?
2. What are the service-users' views of the vocational rehabilitation service received, in terms of both experience and outcome, and how does this compare with service providers' perspectives?
3. What is the cost of service delivery, and what is the cost utility?

Evaluation methodology

These questions are answered using both quantitative and qualitative methods, within a framework of Realistic Evaluation.¹³ This methodology presents a context-mechanism-outcome (CMO) configuration for developing and testing claims about effective interventions, stating *what it is about an intervention that works, for whom, and in what circumstances*.

Quantitative data is collected from service users at baseline, and repeated at six months, incorporating the EQ5D, a modified Client Services Receipt Inventory, and a modified General Self Efficacy Scale, designed to enable a cost-benefit analysis. Data will be collected from both intervention and comparison groups, to enable a comparison of outcomes, costs, and perceptions of services.

Qualitative data collection includes one-to-one in-depth interviews with service users and service providers, focus groups with service users, and non-participant observation of vocational rehabilitation interventions.

The evaluation is being carried out by a research team based at the Institute of Neurology at UCL, led by Dr Diane Playford. The team has substantial experience of evaluating vocational rehabilitation services in multiple sclerosis, stroke and other longer term neurological conditions, as well as experience in cancer rehabilitation research.

EARLY FINDINGS

For the majority of the pilot projects, the first few months have been devoted to recruiting staff to deliver the intervention, and setting up and publicising their services. The projects are now beginning to deliver services to patients and collect baseline quantitative and health economic data.

At this early stage, data for this report has been gathered through interviews and discussions with the service providers in each project, and with service users from two of the pilot projects. In-depth telephone interviews have been carried out with three patients. In addition, a member of the research team has observed two vocational rehabilitation sessions with clients, as well as a support group facilitated by the vocational rehabilitation specialist, where employment issues were the main focus of the meeting.

From these discussions, interviews and observations, five emerging themes have been identified.

1. Patients want attention to be paid to work issues at an early stage in their illness, and then revisited during the course of treatment and follow-up

A diagnosis of cancer is a shock, and patients have a great deal of information to take in and to come to terms with in the early stages of their illness. While it is possible that employment issues might not be at the forefront of patients' concerns, their importance should be flagged by health professionals, indicating the availability of support and advice when needed.¹⁴ Health professionals should remain vigilant throughout patients' treatment and follow-up to work-related problems.

"Oh yes, definitely, without a doubt, having information early on that there is support out there is absolutely essential. But that's not enough on its own. It's an issue that's not going to go away, and there are plenty of people like me quite far down the line, after treatment even, who are still struggling. It's not just a matter of – here, here's the information pack, go away and read it. It does need to be revisited."

– H, Teacher

"I just wish I'd found her [the vocational rehabilitation specialist] sooner. There were so many things I wasn't told about, that I just had to muddle through, like how to manage the fatigue, how to balance work and the rest of life, to take proper breaks – things that I now understand, now that it's been properly explained."

– V, Recruitment Consultant

Being diagnosed with cancer is seen as a time to take stock – both health professionals and patients talk about the opportunity it presents to re-evaluate life, to think about what is meaningful, to decide where to direct one's energies. However, a decision to change career or stop working can be detrimental if patients are not supported to think carefully through the consequences.

"I went back to work for a while after my treatment but my heart wasn't in it. Being an accountant for whatever time I had left just didn't feel right. I decided to resign, and travel – I wanted to reassess my whole life, really give myself time to think about what was important to me. When I came back, I decided that I could use my financial skills more creatively – working in a charity, for example, doing communications and fundraising. But it was harder than I thought it would be to get a job. Other applicants had experience and I lacked any. The longer I struggled, the more I felt really low and worthless. D [the vocational rehabilitation specialist] has been so helpful. I have a plan now. Before, everything was drowning me – career, finances, health worries. She helped me to break it all down into manageable chunks, and to start thinking practically and strategically. Perhaps you would think, 'Why can't he manage to do that for himself?' and if I was looking objectively at someone else's situation, I'd be able to say to that person, 'You need to do this, do this, do this.' But when it's you, you feel like you are being sucked into a whirlpool, you can't organise your thoughts. It was vital for me to have that calm, objective, supportive, positive appraisal of my situation."

– R, Accountant

2. Health professionals inadvertently give patients mixed messages about work

Employment issues do not appear to be raised routinely by health professionals. The focus of consultations with doctors and nurses is on treatment and symptom management. Without an explicit invitation to discuss work issues, patients do not perceive this to be of relevance or interest to health professionals, and do not mention their concerns. Patients are given mixed messages by

health professionals. On one hand, the importance of maintaining a sense of normality and control is encouraged; on the other, patients are advised not to put their health at risk by 'overdoing things'.

During a support group, patients discussed work issues. Together with the two nurses present, they agreed about the importance of work in feeling normal, having a routine, giving structure to your day, gaining a sense of control over your life. One patient described how her diagnosis had impacted on a course she was undertaking. "I was having chemo when everyone else was sitting their exams early in the summer, but the uni was very supportive and I've been keeping up with studying and I was able to take my exams with the others doing resits last week." The nurse beside her looked immediately concerned, and said, "Naughty! You need to look after yourself!"

– Observational data from support group

"Several people have said to me, I should get out of teaching. At our GP practice there is a practice nurse who is lovely – I try to see him rather than the GP when I have a problem because he's been so supportive. He says to me, 'You need to get out of teaching. It's doing you no good. I have family members who are teachers – I know how exhausting the job is.'"

– H, Teacher

3. Line managers are a key point of contact between patients and employers, and do not necessarily have the knowledge and skill to manage a patient's return to work effectively

Line managers are often the patient's primary link with their employing organisation. Where a line manager has poor knowledge of organisational policies, procedures and employment law, this can lead to patients being encouraged to make poor decisions.

"I felt so guilty about all the time I had taken off. She [line manager] was sympathetic, but they were saying they needed to know one way or the other what I planned to do. We had talked about phased return or light duties, but getting that organised was going to take so much effort and involve so many meetings that when she said, 'You could always just resign,' I started to think that that might be the easiest thing for everyone."

– E, Cook

4. Patients are not generally knowledgeable about their rights and responsibilities with regard to employment

Poor advice provided by employers (as illustrated above) can combine with patients' own lack of knowledge about their rights and responsibilities regarding work, which can lead to confusion and distress.

"After my year out of work, I got a temporary job back in accountancy. I decided not to tell my line manager that I'd had cancer, and I had a terrible time. She kept setting impossible targets for me, and when I eventually did explain my circumstances she blew up and said I was in breach of my contract for not having been honest with her. The company transferred me to a different manager, but it was a very damaging experience that really knocked my confidence."

– R, Accountant

There is a great deal of information available for patients and for employers, through Macmillan Cancer Support and via occupational health and human resources departments, but patients do not routinely access these resources, either because they do not know that they exist, or where to look.

5. Specialist vocational rehabilitation services can predict and pre-empt problems that patients may not (yet) be aware of

Expert vocational rehabilitation advisers are able to see problems (or potential problems) that patients may not be aware of, and can anticipate difficulties, in some cases solving these before they even arise.

“I went with H [patient] to see her employer to discuss the adjustments that could be made to enable her to return to work. I wanted to be sure that they weren’t going to do what they did last time when they offered her a graded return to work and then scheduled her two classes one at the beginning and one the end of the day, which meant she had to remain at the school all day. This time, one of the things we talked about was her difficulty with standing for any length of time. Her employer said, ‘No problem, we can give you a high stool [to sit at the laboratory bench].’ H replied, ‘Yes, thank you,’ but I was able to explain that a small hard stool with no backrest was not likely to be sufficient in helping H to manage her fatigue at work.”

– A, Vocational Rehabilitation Specialist

“D [vocational rehabilitation specialist] could see that I was in a downward spiral. She has helped me to put together a plan and a checklist – I have things I need to do everyday, steps towards getting a job. Otherwise I wake up in the morning and think, ‘What am I doing?’ The day is just a blank page. It’s dispiriting.”

– R, Accountant

IMPLICATIONS OF EARLY FINDINGS

1. Patients’ work situation and employment needs should be an integral part of the holistic assessment process throughout the course of the patient’s illness.
2. There needs to be a shift in culture in the provision of cancer services towards a recognition of the benefits of work, and an understanding of the health professional’s role in facilitating patients to remain in employment where appropriate and feasible. Health professionals need to be aware of the overt as well as the covert messages they provide to patients about work.
3. Vocational rehabilitation specialists have an important role in providing education and training for:
 - Health professionals, on the importance of work, the consequences for patients of employment difficulties, and on resources available.
 - Employers, including line managers, on supporting a person with cancer in the workplace, and on organisational policies, procedures and basic aspects of employment law.
4. Information needs to be made available to patients – via a range of sources, such as leaflets, posters, printed booklets, websites, health professionals, advisors at cancer information centres – both to provide facts and details about employment, and to signpost patients to experts and specialist services where these are required.
5. Expert vocational rehabilitation advisers have an important role in responding to patients’ explicit difficulties, as well as pre-empting problems that the patient will not necessarily be aware of and acting – in partnership with the patient – as the patient’s advocate.

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 11. Research currently in progress at UCL and the University of Nottingham in other health conditions (led by members of the evaluation team for this project, Drs Diane Playford and Kate Radford) suggests that the following are potential service user outcomes of vocational rehabilitation:
 - Job retention.
 - Return to work after single or multiple episodes of extended sick leave.
 - Withdrawal from work on health grounds.
 - Entry to alternative occupation.
 - Transition between education and employment.
- Key components of vocational rehabilitation services include:
- Early and rapid intervention.
 - Responding to service user needs throughout the course of their condition.
 - Vocational assessment – the global appraisal of an individual's work programme, functional capacities, and social and behavioural characteristics.
 - Employment assessment – assisting individuals to make an informed choice about an appropriate job.
 - Facilitating single or multiple work adjustments, including provision of explicit verbal and written advice, worksite meetings, provision of specialist equipment and adaptations, assistance with travel to work.
 - Engagement with employers over time.

- Cooperation and collaboration with other service stakeholders, for example Jobcentre Plus, GPs, and legal advice services.

This vocational rehabilitation project evaluation will test these propositions to ascertain their relevance to vocational rehabilitation in cancer, suggest modifications where appropriate, and identify additional outcomes and/or mechanisms.

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