

**Returning to work:**

**Cancer and vocational  
rehabilitation.**

**Report of a scoping study  
for Macmillan Cancer Support**

**February 2008**



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CANCER SUPPORT**

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## Executive Summary

### Key findings

There are few services available to support people with cancer in returning to work. There are many gaps in existing services as well as problems with access to the services that are available:

- Although more working age cancer patients are surviving the disease their vocational rehabilitation needs are not high on anyone's agenda. There is poor awareness amongst health, rehabilitation and employment professionals about the long-term work-limiting effects of cancer. This inevitably impedes effective return to work planning.
- NHS rehabilitation professionals, such as occupational therapists (OTs), have a narrow focus on hospital discharge and do not have the capacity to provide vocational rehabilitation. Other health professionals (eg cancer nurse specialists and GPs) have neither the capacity nor the occupational health skills to support people returning to work.
- Jobcentre Plus services are mainly focused on helping people on incapacity benefits get back into work, and there is less available for people who want to remain with their current employer. It is not known how well these services meet the needs of people with cancer or how easily people with cancer are able to access these services. More research is needed.
- Occupational health (OH) services are only available to people who work for large organisations with an in-house OH department or for employers who are prepared to buy in this service. There is currently little OH provision for people who work for small and medium-sized employers (SMEs).

## Introduction

1. This report summarises the findings from a scoping exercise that aimed to find out about the current provision of vocational rehabilitation services for people with cancer. It also sets out some of the steps needed to improve provision in this key area.
2. The results are based on short telephone interviews with 14 professionals providing cancer care and/or vocational rehabilitation.

## General overview

3. Supporting people with cancer in returning to work is becoming a much more important issue because so many more people are surviving cancer treatment. The numbers are expected to increase in future.
4. Planning a return to work for people with cancer is not high on anyone's agenda. There is a general lack of awareness of the need for vocational rehabilitation and uncertainty about who should be providing this service.
5. There is also a general lack of awareness of the long-term effects of cancer treatment. This information is essential for all stakeholders – people with cancer, health professionals and employers – to plan a successful return to work.
6. The vocational rehabilitation needs of people with cancer vary enormously depending on their individual circumstances. Meeting these needs requires different types of service. This could include a multi-tiered model of support providing both basic and specialist advice.
7. The evidence suggests that it is helpful for people to start thinking about a return to work right from the beginning of their cancer journey. This shapes people's attitudes and beliefs, and is crucial for successful rehabilitation. Encouraging health professionals and people with cancer to discuss returning to work much earlier would require a change in NHS culture.

## Services and support provided via the NHS

8. There is a general lack of rehabilitation services in the UK as a result of long-term under-investment.
9. OTs could provide vocational rehabilitation to people with cancer, but most services are already stretched to capacity. OTs are focused on managing hospital discharge in order to meet Government targets, or supporting people who are very ill, either during their cancer treatment or at the end of life.
10. Clinical nurse specialists provide general advice and support to help people with cancer manage the practical aspects of their lives, including work. However they focus on supporting people during treatment. They do not receive training or guidance on providing vocational rehabilitation.
11. GPs have been focused on sickness certification. They have neither the capacity nor occupational health skills to advise or support people with cancer who want to return to work.

## Services and support provided via Jobcentre Plus

12. Jobcentre Plus provides a wide range of general services to help people find work. The Pathways to Work programme is targeted at recipients of incapacity benefits to help them get back to work, but there is little on offer to help people who become sick or disabled to remain with their current employer.
13. It is not known how well Jobcentre Plus services meet the needs of people with cancer or how many people with cancer make use of them.

## Services and support provided via employers/ occupational health services

14. Access to OH services are very limited and mainly confined to larger employers with in-house occupational health departments or employers who can afford to buy-in these services.
15. Many small to medium sized enterprises (SMEs), cannot afford these services. Government schemes to address this shortfall have not been successful to date, though further investment in advice and support services was announced at the end of 2007.

## Suggestions on how to improve vocational rehabilitation for people with cancer

16. Interviewees were asked for their views on how to improve vocational rehabilitation for cancer patients. Key suggestions included:
  - Raising awareness amongst health and employment professionals about the rehabilitation needs of people with cancer.
  - Developing new standards of cancer care and integrating vocational rehabilitation into health and social care assessments.
  - Investing in OT services to increase capacity and raise awareness of their potential to fulfil this role.
  - Using existing best practice evidence to develop and pilot new models of vocational rehabilitation for cancer patients.
  - Developing tools and practical guidance for employers and people with cancer to work together to manage a successful return to work.

## Recommendations

17. Cancer specific occupational health tools and resources should be developed for health professionals, employers and patients.
18. The Department of Health should work with Macmillan to explore how health professionals can best support people in returning to work after cancer.
19. Stronger links need to be made between Jobcentre Plus and the NHS so that health professionals are better able to signpost patients to Department for Work and Pensions (DWP) employment services. Information and referral triggers for employment and rehabilitation should be built into care pathways.
20. The lack of capacity in both vocational rehabilitation and occupational health services must be urgently addressed. The Government should explore ways of improving access to rehabilitation services for SMEs and consider whether this is best achieved through a substantial investment in NHS rehabilitation services or whether other models for funding/ provision should be developed.
21. There is a need to develop and test effective models for supporting people with cancer to return to work. Rehabilitation pilots could help to determine:
  - whether there is an optimal point of intervention for people with cancer
  - whether a cancer occupational health specialism should be developed
  - whether the right NHS levers and incentives are in place to deliver better return to work services
  - whether a multi-tiered model of support is needed with generalists (GPs, nurses) providing basic occupational health advice and rehabilitation professionals delivering more specialist support.
22. Additional research is needed to collate best practice, review the international evidence and look at rehabilitation provision in the devolved health administrations in Scotland, Wales and Northern Ireland.
23. Further research is required to look at the experiences and needs of people with cancer using Jobcentre Plus employment services to determine whether their specific needs are being met.

# 1. About this report

- 1.1 Each year around 90,000 people of working age are diagnosed with cancer<sup>1</sup> and the numbers surviving cancer are increasing. Ten year cancer survival rates have doubled in the last 30 years, with 46% of people diagnosed with the disease surviving for 10 years or more. Returning to work has emerged as a major challenge.
- 1.2 The issue of cancer ‘survivorship’ has also come to the fore in Department of Health policy. The recently published Cancer Reform Strategy included a commitment to establish a new National Cancer Survivorship Initiative in partnership with Macmillan and other cancer charities. ‘Back to work support’ will be a key component of this initiative. The Strategy also recommended that *‘Commissioners should make sure that information for people who work and have cancer is made available to patients as soon as they are diagnosed. Advice on returning to work should be available for all patients of working age’*.<sup>2</sup>
- 1.3 Getting sick and disabled people back to work has been a growing Government concern in Britain for the last 15 years. In October 2005 the Government published a cross-departmental strategy aimed at improving the health and well-being of working age people<sup>3</sup>. The most recent welfare reform green paper also emphasised the need to manage sickness absence and help sick and disabled people get back into employment. Information and support are recognised as crucial: *‘Most people who claim incapacity benefits expect and hope to return to work. The key to supporting these aspirations is to provide tailored, flexible support and information early [...]’*.<sup>4</sup>
- 1.4 Recent research conducted by Macmillan revealed that cancer patients face a range of problems getting back to work, but that the evidence base on what return to work interventions are most effective is extremely weak.<sup>5</sup> An alarming finding was that many cancer patients are returning to work without any medical or rehabilitation advice or support. This scoping exercise was therefore commissioned to identify:
- the points during the patient journey when information, advice and services relating to vocational rehabilitation<sup>6</sup> are provided to people with cancer, as well as who provides this service and how it is provided.
  - how the system could be improved to ensure that the right information and support is provided at the time when people need it.

<sup>1</sup> Department of Health, *Cancer Reform Strategy*, December 2007, p80

<sup>2</sup> Department of Health, *Cancer Reform Strategy*, December 2007, pp80-81

<sup>3</sup> Department for Work and Pensions, Department of Health, Health and Safety Executive, *Health, work and well-being – caring for our future*, October 2005.

<sup>4</sup> Department of Work and Pensions, *In work, better off*, July 2007, p11

<sup>5</sup> Macmillan Cancer Support, *The Road to Recovery*, 2007

<sup>6</sup> Vocational rehabilitation refers to the wide range of services and support that enable a person with disabilities to gain employment or return to work, from counselling through to computer training.

- 1.5** The focus of this scoping exercise has been the provision of vocational rehabilitation services – via the NHS, Jobcentre Plus or employers. This does not include applying for benefits, taking early retirement or understanding employment rights under the Disability Discrimination Act. From the patient perspective the two main issues are:
- getting the information needed to make a decision about when to return to work
  - getting the appropriate support to be able to find a new job or stay with a current employer.
- 1.6** The findings in this report are based on short telephone interviews with 14 professionals providing cancer care and/or vocational rehabilitation. A list of the interviewees can be found in Appendix 1.
- 1.7** This scoping exercise has focused on services in England and more work needs to be done to explore whether the issues are the same for all four nations.
- 1.8** The report is structured as follows:
- Section 2:** Returning to work when living with cancer: cross-cutting issues
  - Section 3:** Services and support provided via the NHS
  - Section 4:** Services and support provided via Jobcentre Plus
  - Section 5:** Services and support provided via employers/occupational health<sup>7</sup>
  - Section 6:** Suggestions for improving rehabilitation provision
  - Section 7:** Recommendations and next steps

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<sup>7</sup>Occupational health services ensure safety in the workplace and provide health services for the workers. This includes providing support to a person to help them return to work.

## 2. Returning to work when living with cancer: cross cutting issues

### Vocational rehabilitation is becoming increasingly important for people with cancer

- 2.1 Supporting people with cancer in returning to work is becoming a much more important issue because so many more people are surviving cancer treatment. Every interviewee commented on the growing importance of this issue, valued research being done in this area and supported Macmillan in taking a lead.

### Issues specific to vocational rehabilitation for people with cancer

- 2.2 The issues that people with cancer face when returning to work may be similar to those experienced by people with other health conditions (eg stigma, lack of understanding by work colleagues, low confidence) and many of the health concerns may be the same (fatigue, depression, cognitive problems).

*‘When you look at the actual issues involved in returning to work, they are very, very similar in everybody, whether you have cancer or mental health problems.’*

**Shaw Trust Manager**

- 2.3 However, there are areas specific to cancer rehabilitation, where knowledge of the cancer journey is essential to developing a successful return to work plan. These include:
- understanding the trajectory of the illness and therefore knowing when is the best time to intervene
  - knowing when and how people with cancer get access to rehab services

- understanding how particular symptoms have arisen (eg as a side effect of chemotherapy) and the likely length of their duration

- knowing the risk of late side effects of different cancer treatments eg late radiation damage, or nerve damage caused by some chemotherapy drugs.

- 2.4 Many professionals who could play a key role in supporting people with cancer back to work lack this knowledge and understanding (see below).

### Meeting the vocational rehabilitation needs of people with cancer

- 2.5 The vocational rehabilitation needs of people with cancer vary enormously depending on individual circumstances. Factors that are likely to have an influence include:
- the type of cancer and treatment
  - response to treatment and experience of side effects
  - how long people stay off work
  - the type of work they do
  - whether a person with cancer wants to or can return to the same employer or whether they want or need to change jobs
  - levels of confidence and ability to cope
  - level of support from friends and family.

2.6 Therefore the type of service required by each individual will be very different. Some people might simply want some information to hold a pre-return-to-work conversation with their current manager. Others might need considerably more support to overcome any psychological barriers; while others may require more practical support eg training to be able to apply for a new kind of job.

2.7 This means that, as one interviewee commented 'No one size fits all'. It may be necessary to develop a range of services provided by different professionals. This could include a multi-tiered model of support with:

(a) GP practice staff, cancer doctors and clinical nurse specialists providing general information/advice

(b) rehabilitation specialists ie occupational health physicians and specialist nurses (occupational health professionals – OHPs) and occupational therapists (OTs), providing a more comprehensive service.

2.8 An important role for nurse specialists and/or GPs may then be in helping a person decide whether they are ready to start vocational rehabilitation and what kind of support they need:

*'The question is whether the person with cancer is up for doing it. A nurse can help the person make a decision based on a simple assessment: How long can you sit for? How long can you concentrate for? How far can you walk? How long can you stand for?'*

**Consultant in rehabilitation medicine**

*'At what point do you put patients into rehab? Is it immediately post treatment, as soon as they are fit enough to do it?'*

**Network Allied Health Professional (AHP) Lead**

*'The big issue is when is the right intervention time? Because that would differ so much for so many people. So there is never a single right time – it has to be on an individual basis. But early intervention is of paramount importance.'*

**Shaw Trust Manager**

### **Information and understanding about cancer survival need to be improved**

2.9 There is a general lack of awareness of the long term side effects of cancer treatment and a lack of detailed knowledge as to what these side effects are. This is an issue for all stakeholders: health professionals, people with cancer and employers.

*'GPs would value specific information about the long term effects. It would be good to be able to advise on the more general things.'*

**GP**

*'It would be good to find if there's an evidence base - any epidemiological studies of long term effects of cancer treatment. It's not coming out in the OH literature...This information is very important from an OH perspective – are treating clinicians familiar with this data?'*

**Occupational health professional (OHP)**

*'People see that you've had diagnosis, surgery and chemotherapy and six months down the line they think you should be better... there's an expectation that you should go back into work and carry on as you did previously, when things may not be the same for years after. So people with cancer need help to have a conversation that says "Yes I am better but I am still feeling the effects of chemotherapy" or we need to be involved in those conversations.'*

**OT**

*'A lot of this is about education of HR – so they know how cancer is treated and what to expect during the treatment and in the long term – how long might someone feel fatigued after chemotherapy?'*

**OHP**

- 2.10** All professionals need a better understanding of the long term effects of cancer treatment, if they are to support people more effectively:

*'There is a book Fitness for Work that briefly covers the normal treatment pattern and expected return-to-work dates for a wide range of illnesses including cancer – it's not widely used outside of occupational medicine... I'm not sure it really covers all of the issues ... so I'm not sure that OHPs have got all the information they need to make a thorough evaluation.'*

**OHP**

*'As much medical information as possible is of value, because you need to be able to be very clear as to what is realistic and very often people need answers, "Why is it I'm still tired nine months down the line after chemotherapy?"... People need a good understanding of why they're feeling like they are in order to work constructively with the strength they've got.'*

**OT**

- 2.11** People with cancer also need more information about managing both the short term and long term side effects of treatment and to know what's 'normal' in the context of work.

*'Often people go through various phases of treatment which may take a lot of time and they are often stressed by the process... this delays their return to work and leaves people in limbo... is it reasonable to take time off for treatment or should they be back in work? Are they being a bit lazy? Some clear guidance might be quite helpful, essentially permission giving for what is generally considered appropriate... people often don't have a benchmark to compare themselves against.'*

### **Support needs to be offered from the beginning of the cancer journey**

- 2.12** The evidence suggests that it is helpful for people to start thinking about a return to work right from the beginning of their cancer journey. This shapes people's attitudes and beliefs, and is crucial for successful rehabilitation. Encouraging health professionals and people with cancer to discuss returning to work much earlier would require a change in NHS culture.

*'The thing about the NHS, it's an organisation based on labels and illness not on function. It should be more about what people can do and what can help them to do a bit more. So all the people involved in cancer care need some very good clear comms messages about return to work being about a return to normal life – some very basic information to start the conversation.'*

**OHP**

*'The first thing is to think about employment – it helps if cancer doctors are thinking about it, as this will be communicated to the GP and other members of the Multi Disciplinary Team (MDT).'*

**Consultant in RM**

*'Asking people about their employment forms part of my first assessment of what people need. But not everyone (amongst the patients) thinks to mention this.'*

**CNS**

*'Someone who has got the trust of the patient needs to say... there's a reasonable expectation that you'll be able to go to work at the end of all this and we'll provide the support you require during your treatment.'*

**OHP**

- 2.13** This would have a big impact on the likelihood of successful rehabilitation.

*'People's views on things are set very early – after the shock of diagnosis. This influences their expectation of their future work life. For those people who actually end up not returning to work, my personal view is that the issues revolve around the psychological impact of the diagnosis and their vision of the future.... It would be worth exploring whether that tallies with the medical advice [they were given].'*

**OHP**

*'It's essential to get people to keep returning to work in their mind to make it successful.'*

**OT**

## 3. Services and support provided via the NHS

### Overview

**There has been long term underinvestment in rehabilitation services in the UK**

- 3.1 Many interviewees commented on the general lack of rehabilitation services in the UK. This reflects long term under investment and contrasts with other countries where rehabilitation has been taken more seriously.

*'Rehab specialists are pretty thinly spread. We've got one for our area that really looks at people post spinal injury – but it maybe that his expertise would be more generally applicable.'*

**GP**

*'Cancer rehab has been taken more seriously in Europe for many years...'*

**Consultant in RM**

- 3.2 Although there has been massive investment in cancer services in recent years, little has been invested in rehabilitation. Most of the funding has been targeted elsewhere.

*'Rehab locally feels quite thin on the ground. I'm sure we're not the only network to say that. One of the reasons is that a lot of the NHS targets are stacked at the front-end of the patient's journey, like hard targets for waiting times – of course they are important – but the problem is the whole focus then is on the hard targets because they are the must-do's. What gets left behind is the rehab... So what we've got is more patients going through the system but with about the same level of rehab, so it's spread thinner.'*

**Network AHP Lead**

- 3.3 Specialist rehabilitation services also appear to be getting cut back.

*'Some people may need the help of an occupational psychologist. But these teams are being reduced massively, when actually they may be needed even more.'*

**Network AHP Lead**

**The provision of rehabilitation services for people with cancer is severely limited**

- 3.4 Rehabilitation for people with cancer tends to be provided by OTs or clinical nurse specialists, usually as part of a team. The OTs can be members of specialist teams (cancer Multi Disciplinary Teams (MDT) or Palliative Care Teams) or generalists based in rehab teams in the community.

There are a few areas where it is working well, often with Macmillan's support, but overall provision seems to be patchy and under-resourced.

*'Only some areas have cancer focused rehab teams. Where these don't exist, people with cancer would be referred to community therapists, who have a very, very mixed workload. For example with a community physio, out of 100 patients, only three or four may have diagnosis of cancer... Community therapist teams do have generalist knowledge, which is sometimes OK, but not always sufficient.'*

**Network AHP Lead**

**3.5** Vocational rehabilitation currently seems to be a very minor part of the general service. None of the health professionals interviewed had experienced much demand for support in returning to work. On average they had seen only two or three cases in the previous year. In the case of OTs, this seems to be due to a lack of referrals by other health professionals, due to low levels of awareness of the need for vocational rehab. In the case of the GP, this seems to be due to the fact that the majority of his cancer patients are beyond working age.

*'It's very rare to address return to work issues – we saw maybe three people in the last year.'*

**OT**

*'We have one or two working age people a year going back to work – most of our cancer patients are over 65.'*

**GP**

**3.6** Even though helping people with cancer return to work had so far been a very small part of what people did, they were all confident they could provide this service should the need arise. The major concern was whether they would have the capacity to deliver this service in addition to their current workload.

*'The general oncology teams include physios, OTs, speech and language therapists and dietetics. Sometimes the focus is on palliative care but they could have a role in work rehab, if there was capacity to do it.'*

**Network AHP Lead**

*'We have a very high caseload just managing the palliative care cases. So if we got more referrals for vocational rehab, we may not have the capacity – we might not be able to meet the demand.'*

**OT**

*'We are a small team and don't know if we have capacity to provide [vocational rehabilitation]. We have not promoted ourselves as we may not be able to cope with the demand.'*

**OT**

**3.7** Some people expressed concern that currently people with cancer are poorly served by the NHS after their cancer treatment has finished. It seems that only the most proactive patients are able to get the follow-up care they need.

*'Once they [cancer patients] are signed off from active treatment, they feel dumped. They have no where to go as they don't have the label of cancer anymore. That's a lonely place to be... A lot of people fall through the gaps. It seems people don't know where to turn to for follow-up care and advice – they would need to be very proactive to find it.'*

**OT**

*'We did help one person with an assessment in their workplace, as he was using a wheelchair and finding it hard to manoeuvre. But he had to ask for the help he needed. He was a senior manager so he had the confidence to do that... the services are available for people who are used to pushing for what they want. There may be many more people who don't have that confidence or know who to go to.'*

**OT**

### Health professionals are generally unaware of the need for vocational rehabilitation

**3.8** Many people commented that currently cancer doctors rarely discuss returning to work with their patients. Similarly OTs and rehabilitation doctors rarely consider the relevance of their services for cancer patients.

**3.9** Returning to work is not always a formal part of clinical assessments for cancer patients. The NICE guidance on *Improving Supportive and Palliative Care for Adults with Cancer* states that ‘work and leisure activities’ should be assessed routinely for rehabilitation. However, this is not happening in practice.

*‘Health and social care professionals aren’t thinking to refer people for rehab for return to work.’*

**OT**

**3.10** It seems that assumptions are also being made about people’s ability to cope with returning to work.

*‘Work rehab doesn’t have a high profile – if you’re well enough to go back to work get on with it.’*

**OT**

*‘With younger patients, people [health professionals] perceive they are more able to get over their chemotherapy and just expect them to get on with it and return to work when they feel like it. There is a big gap there still in terms of therapy to assist them in that process.’*

**OT**

*‘We underestimate how much people’s confidence is knocked by cancer.’*

**OT**

**3.11** A few of the interviewees were concerned that some health professionals may assume that people with cancer are simply not going to return to work.

*‘At a generalist level [amongst OTs] there is a belief that people with cancer can’t improve.’*

**Network AHP Lead**

*‘The views of some GPs might be overly pessimistic. They may assume that a diagnosis of cancer should lead to retirement.’*

**OHP**

### There are gaps in health professionals’ knowledge and expertise

**3.12** At present there are few health professionals with the full complement of skills and knowledge to provide specialist support to people with cancer returning to work. Cancer specialists are not familiar with the ‘world of work’:

*‘Nobody is saying “Have you thought about a return to work?” The oncologist isn’t saying it because it’s not their business and they wouldn’t be able to answer the questions anyway – because the average hospital doctor knows nothing about health and safety laws, the Disability Discrimination Act (DDA) etc.’*

**OHP**

*‘The problem is clinicians don’t see work as their role. It’s a huge deficiency in medical undergraduate and postgraduate training, in GP training and nurse training. ...They don’t even know what they don’t know.’*

**OHP**

*'There are no rehab doctors who are specialising in cancer rehab... nor have I ever been approached by cancer doctors to talk about cancer rehab.'*

**Consultant in RM**

- 3.13** At the same time not all rehabilitation specialists are familiar with the experiences of people affected by cancer:

*'Rehab teams know about disability but not the experience of people with cancer and what they have been through.'*

**OT**

*'I'm not sure a generalist AHP would know about cancer. There isn't anyone who knows about both rehab and cancer.'*

**OT**

*'Often people will say "There's nothing I can do for cancer", but quite often it's because people don't understand what they can do.'*

**Network AHP Lead**

### **Making links with vocational rehabilitation services outside the NHS**

- 3.14** Making formal links with vocational rehabilitation services outside the NHS is rare, even within the area of occupational therapy<sup>8</sup>.

*'NHS people are not familiar with services outside the NHS, since this represents the next stage where rehab finishes and where people move onto.'*

**Network AHP Lead**

*'In our patch health and social care OTs work together. Social care OTs look at equipment provision, working with housing associations and councils to look at housing adaptations, while we try and look more holistically and offer care related to health... But co-ordination is not standard. We were the first service to offer that integration.'*

**OT**

*'I have referred people to free computer skills courses – but I'm not an expert on this.'*

**OT**

- 3.15** Many people could see the value of making more formal links. This could become part of the rehab process itself, effectively reducing people's dependence on the health service.

*'The gap is between the hospital and vocational training... you're discharged and you're in that big void of "hang on a second, I've got all these issues and now where do I go"... There needs to be a continuous and holistic link there between the NHS, the Job Centres and the voluntary sector. So once you're taken off the clinical intervention there is a clear vocational link as part of the exit interview.'*

**Shaw Trust Manager**

*'I have never worked with job centres or occupational health departments... If you knew they were the people who could help, it would be fantastic – but they haven't been part of my thoughts up 'til now.'*

**CNS**

<sup>8</sup> Occupational therapy involves treatment to restore a physically disabled person's ability to perform activities of daily living such as walking, eating, drinking, dressing, toileting and bathing. This could include helping with a return to work.

*'Like with our lung cancer rehab group, we are trying to get patients to transfer from health-based rehab into leisure services. We're trying to get patients away from reliance on health services, saying "This is the rest of your life now. You don't need the health service, what you need is the exercise".'*

**Network AHP Lead**

- 3.16** One interviewee also emphasised the importance of avoiding a 'medical model' of vocational rehabilitation. It is important that rehabilitation encourages people to become confident and empowered to make their own decisions. Models of care which are based on people finding their own ways to manage their symptoms (eg peer support groups) are generally viewed to be the most effective.

*'With a catastrophic diagnosis like cancer, people quickly get slotted into a medical model that encourages reliance on it and almost become co-dependent... the question is how do you reduce that co-dependency when people are still linked in to that model because they are receiving annual checks and may still be taking drugs.'*

**Network AHP Lead**

- 3.17** Wherever people receive vocational rehabilitation, it is vital that they receive consistent advice from all the professionals involved:

*'It's important to have consistency of advice between the three important players - the consultant oncologist, the GP and the workplace adviser. The patient is right in the middle of that triangle. What would be worse than what we have now is conflicting advice. That would create so much anxiety and difficulty.'*

**OHP**

- 3.18** The remainder of Section 3 will consider the specific issues relating to rehabilitation services provided by:

- (a) Occupational therapists
- (b) Clinical nurse specialists
- (c) Rehabilitation programmes
- (d) GP practices

**(a) Occupational therapists (OTs)**

***Vocational rehabilitation is not a priority for OTs***

- 3.19** Government targets in recent years have changed the focus of OT services from occupational therapy to more general rehabilitation and hospital discharge. This is true for OTs based in acute Trusts or in the community.

*'Twenty years ago OTs were there to get people back to work, but that's all been swept up in the Government's drive to clear hospital beds. OTs tend to focus on getting people back home, but not necessarily back to work.'*

**Consultant in RM**

*'There is a massive emphasis on reducing the length of stay and ensuring patient discharge takes place, so therefore the majority of the OTs time is spent on discharge planning as opposed to rehab... OTs are fantastic at discharge planning – but it's only part of their role. They are not fulfilling a big rehab need.'*

**Network AHP Lead**

*'OTs mostly focus on getting people out of hospital in secondary care and then keeping people out of hospital in the community... It's very pressured in hospitals... they have a bit more time to address quality of life issues out of hospital... this still isn't as specific as supporting a return to work, it's more about general functioning.'*

**OT**

- 3.20** Within the specialist cancer teams, the pressure on OT resources means that priority is often given to people who are most ill, either to support them through treatment or to provide palliative care.

*'We do see people that have a diagnosis and work with them in rehab to get over the effects of treatment. Mostly it's seeing people through palliative chemo and radiotherapy.'*

**OT**

*'The sum of what of we do is the prevention of people coming back into hospital - that automatically targets people who aren't as well.'*

**OT**

- 3.21** Access to community based OTs is often via social services, and again priority is given to people thought to be in greatest need.

*'They [social care OTs] have eligibility criteria to work to and really their criteria are that they work with substantially and permanently disabled people. If someone contacts social services and says "I've had cancer", I don't know whether social services would see that as a priority for their workload. I expect that in the majority of places work rehab is not being offered.'*

**OT**

### **Lack of understanding of the role of OTs**

- 3.22** It seems that other health professionals are not aware that OTs would be able to provide vocational rehabilitation.

*'Other people's perceptions of what we do are maybe why we get few referrals for work rehab.'*

**OT**

*'A lot of the time when we refer to OTs it's to get patients home from hospital... I personally have never thought that the OT could be part of rehabilitating someone to get back to work.'*

**CNS**

*'It would be a battle to get others to refer people to us for work rehab, because we would need to raise awareness amongst other health professionals as to what they need to be doing.'*

**OT**

### **OT services are under-resourced**

- 3.23** As a consequence of long term under investment, there are too few OTs to meet demands and OT services are therefore overstretched. This makes other health professionals reluctant to make referrals except for the most urgent cases.

*'For a long time we only had one OT for the whole of oncology and he was always pulled from pillar to post. So we always thought "Oh no, I've got to do another referral...They were always overloaded".'*

**CNS**

**(b) Clinical Nurse Specialists (CNS)**

- 3.24** Clinical nurse specialists can provide general advice and support to help people with cancer manage the practical aspects of their lives, including work. They also manage referrals to rehabilitation specialists, if these services are locally available.

*'If there are physical issues preventing women from going back to work, then I'd sit with them and devise a list of what their current symptoms are and work through that with them and the other members of the MDT... The other aspect is the psychological aspect. We're quite lucky in that we have a designated clinical psychologist, so if we need to do both physical and emotional aspects – we would organise a referral.'*

**CNS**

- 3.25** Nurse specialists may be better placed than cancer doctors to manage this aspect of care.

*'Nurse specialists tend to do the referrals. We can access other team members easily... We argue the patient's point and we can just get on and do what's needed.'*

**CNS**

- 3.26** However, it seems that work is only discussed in the context of making a decision about whether to continue working through treatment, rather than thinking about returning to work once treatment has finished.

*'Often women want to know if they can continue to work through treatments.'*

**CNS**

- 3.27** It also seems that nurse specialists are not given much guidance or support in providing this service.

*'It's very vague. There's no guide. There's nothing out there that's set in stone that says this is what you can do to help support cancer patients – rehabilitating them to go back to work. It's solely through previous knowledge and experience and going through it with previous patients... Even though everyone is unique, there's got to be some foundation work that you can probably apply to everybody.'*

**CNS**

*'There's probably a lot of work that people do automatically but nothing has been formalised at network level or nationally that could be of help to health professionals or help patients to do it for themselves.'*

**CNS**

### (c) Rehabilitation programmes

- 3.28** A number of vocational rehabilitation programmes have been developed that have proved successful for people with other long term conditions such as chronic fatigue and low back pain. These combine the psychological and physical support that a person needs to return to work. A similar programme is being developed and piloted in the Manchester Cancer Network for people with cancer.

*'A group of patients would attend sessions three times a week for five weeks. They'll have a whole programme around physical exercise, knowledge of their condition, dealing with that condition and the psychological aspects of it, aiming to get that positive thinking message across... Some people will think the physical problems are massive barriers, "I can't swallow, I need to drink all the time, I can't possibly go to back to work." But some of those people could think more positively around the constructive things they could do... The danger is if we don't approach that psychological side, then hundreds of people will be worried well, not getting back to work.'*

**Network AHP Lead**

### (d) GP practices

- 3.29** Up until recently the main role for GPs in relation to work has been sickness certification. This has created a culture where people are viewed simply as either fit or unfit for work. However, GPs could play a more supportive role if they had a better understanding of vocational rehabilitation and easy access to sources of good advice. This would mesh well with current plans to increase GPs' active involvement in the follow-up care of their cancer patients.

*'GPs don't seem to do a lot other than suggest when's the right time to come off sick leave. There's not a lot of structured advice available.'*

**OT**

*'Certification makes things difficult...with the certificate we have say you're fit or not fit for work, which makes it difficult to advise people. Some clear routes to reliable information would be helpful... Our role should be signposting rather than delivering – we're not the experts.'*

**GP**

- 3.30** There was some doubt as to whether GPs have capacity to take on a vocational rehabilitation role and a suggestion that practice nurses would be better at providing this service.

*'The burden on GPs gets bigger and bigger every day with everything everybody wants them to do and they won't do this additional stuff. But they do want what's best for the patient and so they cannot be ignored because they are so influential as the patient advocate.'*

**OHP**

*'Practice nurses are a great resource. Given the right skills and training they would rise to the task. They are a hugely resourceful group and used to helping people manage other chronic illnesses – a lot of the skills are transferable. But they need it demonstrated to them that they have got the skills – they need information resources so they can respond to the questions that people come up with.'*

**GP**

## 4. Services and support provided via Jobcentre Plus

### Overview

- 4.1 Jobcentre Plus provides a wide range of general services to help people *find* work. These are available to everyone and include training courses, support from a personal adviser, information about job vacancies, CV preparation etc.
- 4.2 There are also specific schemes to help people with a disability or illness either to stay in work or find a new job. These are:
- The **Job Introduction Scheme** – pays employers a subsidy for first few weeks or months to encourage them to employ a disabled person.
  - **Access to Work** – provides support to disabled people and their employers to help overcome work related obstacles. It provides employers with grants for example to make adaptations to premises, purchase specialist equipment and support workers. If a person is starting a new job, it can provide up to 100% of the costs of adaptations, and up to 80% of the costs if they are staying with their existing employer.
  - **Work Preparation** – this is an individually tailored programme designed to help people with a health condition or a disability return to work following a long period of sickness or unemployment. It helps people think about appropriate types of work, work experience, new skills and confidence building.
  - **Specialist advice from a Disability Employment Adviser (DEA)** – these personal advisers specifically help people who are recently disabled, or whose disability or health condition has deteriorated.
  - **New Deal for Disabled People** – this is a voluntary scheme to help disabled people find work with support from an experienced Job Broker. A Job Broker helps people find suitable work and get appropriate training through work placements etc. They also work with employers to overcome some of their prejudice and reluctance to employ disabled people.
- 4.3 For people who are claiming incapacity benefits (IB) there are additional services available through the Pathways to Work (PtW) programme. One of the goals of this scheme is to help people who have been out of work for some time to overcome any barriers that are preventing them from returning to work. The aim is to get people off benefits and into work as soon as possible. At the moment PtW covers 40% of UK, but by April 2008 it will be extended nationally.
- ‘The aim is to intervene at the earliest stage when a person is first applying for IB to get them thinking about returning to work – if we don’t do that, then it may make a return much more difficult.’*
- DWP PtW Manager**

**4.4 The Pathways to Work Programme involves the following steps:**

- Eight weeks after applying for IB, people are asked to attend a mandatory initial interview. The Jobcentre adviser can decide to waive or defer the interview based on discussions with the customer and medical evidence provided by the customer's GP.

*'We don't write people off, but we do need to assess whether it's realistic for a person to attend interviews... we would talk to the person and see how they feel about it and plan the timing of interviews to fit with patient's journey eg defer interviews until after planned treatment.'*

**PtW Manager**

*'The idea is we want these people in the office in the right frame of mind at the right time. But we may need to persuade people who are apprehensive – so we try to build rapport and encourage people to come for interview.'*

**PtW Manager**

- A screening tool is used at the initial interview, incorporating medical and personal information to assess whether people are at risk of being on benefit for a long time ie more than a year. If people are screened out, they can still access the services if they want to. If people are screened in, they are asked to attend five further interviews at monthly intervals. The screening tool is not applied to customers with more severe medical conditions. Existing IB customers can also attend interviews on a voluntary basis.

- Over the course of the five interviews, personal advisers work with individuals to develop a tailored support package. This includes access to all the general services in addition to the PtW specific services. These are:

- **Condition Management Programmes (CMP)** – these are primarily aimed at three groups of claimants: people with mild to moderate mental health conditions, cardio-vascular problems and musculoskeletal problems. The purpose is to help people to better manage their condition and to get back into frame of mind where they can consider working again. The programme is delivered locally through PCTs.

*'CMP can help with general symptoms eg pain and fatigue – providing advice on identifying triggers and taking steps to avoid those situations. People gradually learn what they can and cannot do and what sort of work they can do.'*

**DWP PtW Manager**

*'We start with a health assessment, looking holistically at the person. We ask them to talk about what's been going on with them which is usually complex and quite emotional and not just about their condition.'*

**CMP Manager**

- **Return to Work Credit** – provides £40 per week for the first year to ease the transition back into work from benefits. Customers must work 16 hours or more and earn £15,000 p.a. or less.

- **Job Grants** – for people starting work eg £100 or £250 (for customers with dependent children) – to help with buying clothes etc.
- **In work support** – this helps people stay in work and may involve telephone support, mentoring or sorting out access to work. It may or may not involve employers.

**Do Jobcentre Plus services meet the needs of people with cancer?**

- 4.5 Very little is known about the use of Jobcentre Plus services by people with cancer which makes it difficult to assess how well the services meet their needs. However, evaluation evidence suggests that Pathways to Work works very well for a wide range of people. This is because it tackles the common barriers to returning to work.

*‘The programme is working... We analysed conditions and found it makes no difference with return to work rate... because the condition on the sick certificate is not what’s stopping people from returning to work. They get out of condition because they’re not in the daily routine of work. Barriers build up quickly.’*

**CMP Manager**

- 4.6 It is assumed that PtW works as well for people with cancer as it does for people with other conditions:

*‘I can’t see any reason why it wouldn’t work just as well for people affected by cancer, if they are in the right frame of mind and the right situation. Quite often we find the things that are holding people back are more about the fear of returning to work...it tends not to be linked to their condition.’*

**CMP Manager**

- 4.7 It is not known how many people with cancer make use of the PtW Programme (or Jobcentre Plus services in general). Information about people’s health condition is not recorded beyond general categories of ‘mental health problems’, ‘injuries’ or ‘other health conditions’. The proportion of people claiming IB who have cancer is low (about 1.5%) which suggests that the numbers using PtW services will also be low.

*‘People with cancer tend to be a very, very low proportion of our customers. We’ve only had a handful over last few years.’*

**CMP Manager**

- 4.8 It is also unclear whether the timing of the interventions in the PtW programme is appropriate for people with cancer. A person in work is entitled to 28 weeks sick pay and may then apply for IB. This means there may be an interval of 36 weeks before people receive any advice about returning to work. There is some concern that this is too late and people may have already started to become deconditioned. Most people with cancer have a strong desire to return to work because it signifies a return to normality. However, there may not be a single right time to intervene as it is likely to vary from person to person.

- 4.9 One of the interviewees had carried out a pilot project to evaluate the effects of earlier intervention. They worked with a wide range of people who had been on statutory sick pay for three months. The patients were recruited and assessed in their local GP surgeries. This was found to be more effective for the clients, but there were difficulties with engaging the GPs:

*'The sooner you can get hold of people the better. The pilot proved to be successful for the people we saw, even though they were low numbers... By seeing people earlier we felt we were getting a quicker, more positive response. So we were being more effective and actually capturing people before they lost their jobs as well... but it was difficult engaging GPs. A lot of GPs don't register whether people are on benefits – they have no record. They thought it was a difficult task to find people.'*

**CMP Manager**

- 4.10 Under the Pathways Advisory Service, Jobcentre Plus advisers have been sited in a number of GP surgeries to offer early advice and support. In November 2007 the Government announced plans to treble the number of advisers based in GP practices.

- 4.11 Overall, Jobcentre Plus services tend to focus on helping people to get back into work or to find new work. This means there may not always be the right kind of support available for people who want to stay with their current employer.

*'Jobcentre Plus do not generally see people in work. Most of the services are related to benefits and helping people who are out of work.'*

**OHP**

*'If you are on sickness benefit then we're able to assist. If you're employed then there is a massive gap. We can provide a Staying in Work service which may help fill that gap.'*

**Shaw Trust Manager**

- 4.12 The programmes designed to help people stay in work tend to focus on physical adaptations to the workplace or access to work. These may not always be relevant to people with cancer.

*'Adjustments for people with cancer may not always be structural. A lot are about flexibility and working hours rather than buying a new piece of kit.'*

**OHP**

- 4.13 Jobcentres are unlikely to help with planning a return to work or making changes to work patterns, although a Disability Employment Adviser (DEA) might provide some help with this. This depends on the person getting access to the DEA and the DEA having a good understanding of the issues faced by people with cancer.

4.14 Shaw Trust is one of the providers of the Government's Work Step programme that can be used to help people stay in work. However, there are strict criteria as to who can access it. It is only offered to people who are at risk of losing their jobs because of their condition.

*'The Work Step criteria are strict. You can self-refer or access it through a DEA. But you have to be at the point where your employer has said you are about to lose your job and they have done everything they can reasonably do – but that's a horrible thing to do to someone who has just recovered from cancer... It's a fantastic programme but that [limited access] is a weakness.'*

**Shaw Trust Manager**

4.15 In conclusion there are still many unanswered questions as to how well Jobcentre Plus services meet the varying needs of people with cancer. These include:

- **Are all people with cancer aware that they are eligible for support from Jobcentre Plus?** How do people with cancer who don't claim IB become aware that they can access Jobcentre Plus services? How could health professionals be encouraged to signpost people with cancer to these services?

- **What proportion of people with cancer has access to PtW?** Only those people successfully claiming IB can access the full range of PtW services. What proportion of people with cancer does this represent? What is the best way to reach people who have been on IB for some time and could gain access to PtW voluntarily?
- **Can people with cancer in all parts of the country access the services they need through PtW?** The services provided via the Condition Management Programmes (CMPs) vary across the country. DWP works with PCTs to define the best menu of services within each locality. Are the needs of people with cancer being met in all parts of the UK?
- **Are Jobcentre Plus staff aware of the needs of people with cancer?** Given the general lack of awareness of the problems experienced by people with cancer following treatment, do Jobcentre Plus advisers, particularly DEAs, have sufficient understanding of the cancer journey to reliably advise people with cancer and plan their return to work? Do they need cancer specific tools, training or guidance?

## 5. Services and support provided via employers/occupational health services

### Overview

5.1 Occupational health professionals (OHPs), physicians and specialist nurses, provide the very specialised, tailored support that can help individuals manage and plan a successful return to work, most often with their current employer. The specialist nurses play a very important part in designing, delivering and managing occupational health services. Many of the largest occupational health services in the UK are OH nurse led. They often help with rehabilitation planning and follow up, and provide support to people at their place of work.

5.2 Large companies and organisations typically have in-house occupational health (OH) departments. These are widely viewed to provide the best standard of OH as they usually have sufficient budgets to provide a wide spectrum of services.

*'If people work for a big firm then they have OH schemes... people working for small organisations are much more likely to get a poorer deal... The NHS as an employer is working well. Their OH service has undergone a great change and they're very clear about things like a four week phased return to work.'*

**GP**

5.3 Some companies and public sector organisations choose to buy OH services from external providers. These can work very well:

*'Shaw Trust's Staying in Work Service works with the client to self assess, to work out what barriers there are and provide a 'third party broker approach' between the client and employer. This method has been proven to work and facilitates an amicable and successful return to work wherever possible. However, the Staying in Work Service is a paid for service as funding does not exist to provide this service.'*

**Shaw Trust Manager**

5.4 A problem with bought-in services is that employers are charged per intervention which tends to set limits on what services are offered to employees.

*'It seems reasonable to buy a one-off rehabilitation plan... but if you want to provide on-going support to an employee and monitor the implementation of that plan, that involves lots of meetings which starts to look expensive... now there are six or seven bills after a period of months. So some employers then push OHPs to do the minimum.'*

**OHP**

- 5.5 More importantly not all employers can afford to provide OH services. This is particularly true for small to medium sized enterprises (SMEs) who don't have access to OH departments and may not be able to afford independent advice.

*'It's a bit of a lottery as to what kind of service you get when you return to work, all depending on who you work for and how supportive your employer is... It's the responsibility of the private health insurers – if you pay into an insurance scheme in the workplace and they are affiliated to a back-to-work service then you may be in luck. If you are working in a small back street garage that's a one-man band – then the likelihood is you may not be able to get the help you need to stay in work.'*

**Shaw Trust Manager**

*'Access to OH is available if you want to pay for it. It would be better if OH was an NHS specialty that GPs could refer patients into in the same model as cancer treatment.'*

**OHP**

### **The role of occupational health professionals**

- 5.6 OHPs have emphasised that supporting people to achieve a successful return to work is a highly skilled task requiring an in-depth understanding of different health conditions and the wide variety of issues facing people in the workplace:

*'[OHPs] use a lot of psychological motivational skills. It's not just gathering facts for a rehab plan, but engaging with that person, to give encouragement and a source of support. How a person is handled and spoken to both have a profound effect on the outcome...So it's not an NHS helpline kind of problem – where people can work from a flow chart – it's highly skilled – the person has to be credible and patient has to believe "This is good advice I'm getting here".'*

**OHP**

*'The effects of an illness maybe widespread, physical and psychological. Rehab professionals are highly skilled at sorting these out and helping people to prioritise action to make progress. They are also trained to go and negotiate with employers.'*

**Consultant in RM**

- 5.7 Some OHPs are concerned that generalist health professionals may not have the knowledge or training to provide this kind of tailored support and that a poorly planned return to work may do more harm than good. This is an argument for developing specialist vocational rehabilitation services alongside more generalised services providing basic information and advice.

*'They [other health professionals] may be basing their practice on generalist good intentions – but have no evidence base. When it comes down to the nitty-gritty of work, it's difficult even for a specialist to know if they have never been in that working environment.'*

**OHP**

*'NHS staff are unrealistic about what business is like. They think businesses should do everything to make something happen without reflecting that if they demanded that of their own department, then their department couldn't function. So there's a whole issue that they don't necessarily understand the difficulties employers would face.'*

**OHP**

*'The workplace isn't there to provide integration and sheltered employment for people – the reality is it's a competitive world and you've got to fight for every bit of support available for people with health problems.'*

**OHP**

*'It's better to have a more sophisticated, well informed strategy than one produced by an enthusiastic amateur – and avoid a blanket approach that just says work two days, then three days etc... What's needed is small steps that are successful for that person, if that person falls back, then everyone loses confidence and it's even more difficult to get going again.'*

**OHP**

- 5.8** Similarly an OHP is better placed to provide the information that employers need to make decisions in the workplace. In the absence of OH services, an employer can obtain medical information from the employee's doctor, but this may not contain the information that employers need.

*'The HR or line manager can write to the treating specialist to seek a medical report – with the consent of the individual – but again it's probable that the advice won't be as extensive as if written by an OHP. The treating doctor may not have an awareness of what information could help that employer and may not have knowledge of the world of work.'*

**OHP**

- 5.9** A problem for OHPs is that they often feel caught between working for the employer and the employee. The interests of the employer will often take priority.

*'It's often a difficult role because as a health care professional you want to be an advocate for the patient, but your employer may want you to do that in a way that takes account of the costs to the employer.'*

**OHP**

*'Where OH services do exist their role should be to indicate to the employer what is important to them organisationally – so what reasonably and practically could be put in the workplace to overcome any restrictions and over what kind of period might that be required – that gives the employer the information they need to run their business.'*

**OHP**

**5.10** This also tends to create a focus on financial issues. More attention is given to deciding whether a person is entitled to sick pay or early retirement on the grounds of ill-health, rather than supporting a successful return to work.

*'If the financial pressure was taken away then more resources would be channelled into rehab and support etc... You see that in other countries... and it would be real rehabilitation, not just finding easy jobs for people to do.'*

**OHP**

#### **Meeting the needs of SMEs**

**5.11** The Government has made some attempt at meeting the needs of SMEs for OH advice. These include  
(a) Workplace Health Connect and  
(b) NHS Plus

#### **(a) Workplace Health Connect**

**5.12** Workplace Health Connect (WHC) provides advice on occupational health, safety and return to work to SMEs in England and Wales. It consists of a telephone advice line with an associated website. Employers can also request an on-site visit from one of the WHC specialist advisers if their region is covered.

**5.13** Some of the problems recognised with this service are:

- Although it is cheap, telephone advice only provides the most basic support. The real difficulties lie in turning the information/advice into practical action on the shop floor, which requires more face-to-face support and site visits.
- SMEs are so busy that they rarely have time to seek out the sources of advice that might be helpful to them. More time and energy needs to be invested in advertising such services to make sure they are used.
- The advice is only offered to one party ie the employer, and therefore limited in its application.

#### **(b) NHS Plus**

**5.14** NHS Plus is a network of about 100 OH services in the NHS. These can vary from a part-time GP looking after a rural hospital, through to big MDTs supporting large numbers of people. They exist primarily to look after the 1.3 million NHS staff in England, but also sell their services to other employers, particularly SMEs. Each department has its own menu of services, but all will offer advice on return to work strategies and adjustments to workplaces.

- 5.15 Despite recent investments by the DH, NHS Plus is still not serving a large percentage of population. This is because few OH services have viewed participation in NHS Plus as a benefit. Many see it as taking resources away from the services for NHS employees.

*'A lot of NHS OH departments were already providing services to the community eg routine screening. But this creates a conflict around using public money to do private work... also the profit was not always ploughed back into OH services but swallowed up in the wider budget. In effect this meant a reduction in staff time available to NHS staff.'*

**OHP**

- 5.16 Whilst there are shortfalls in OH provision, particularly for SMEs, in November 2007 the Government announced it will be piloting a new £8m advice and support service for smaller businesses.

#### **Supporting employers so they can provide support for their employees**

- 5.17 Employers play a critical role in determining the success of any vocational rehabilitation. Their support is crucial to how well a planned return to work is implemented. This is particularly true of HR staff.

*'If an HR manager is not supportive of rehab, or thinks it's too complicated or they believe the person is just passing time until they go off sick again – if they have no commitment to modifying jobs then it's difficult to effect change... having HR line managers on board creates a fertile ground for rehab to work.'*

**OHP**

*'Training and education of HR managers is important in moving things along – they can influence other managers and company policies.'*

**OHP**

- 5.18 Support from employers needs to start right at the beginning of an illness and continue all the way through an employee's time off work. This is crucial for their return to work to be successful.

*'There's a tendency for employers to back off... it gets put on the 'too difficult pile'... hiding behind 'it would be insensitive to see this person who's off sick'... but that person may be increasingly isolated from work, becoming depressed, losing an important element of their normality and support network, if managers aren't even coming out to see them even occasionally.... There maybe an expectation that the person with cancer won't be returning to work and that's counterproductive... it becomes a self-fulfilling prophecy.'*

**OHP**

**5.19** Both employers and employees need to be encouraged to plan a return to work as soon as possible. This is in the interests of all parties. The longer people with cancer stay out of work, the less likely they are to return at all, even if their cancer isn't the main reason for not working. Employers also clearly benefit if their employees spend less time on sick leave. But planning an earlier return may require a change in attitude and approach to work.

*'The vast majority of people with cancer who are in work will have good reasons to stay with their employer – because they have employment rights. What people generally do is wait and wait until they are 100% fit and then go back to work. But there are many people who could go back earlier to adjusted work, rather than staying off until they are completely better. That's the classic GP model.'*

**OHP**

*'A planned return to work needs a discussion with the manager. The plan may not be very high tech, for example just working afternoons. The key message is to get employers to think like that – that people can come back before they are 100%, if everything if the workplace is adjusted.'*

**OHP**

**5.20** Some employers also find it very difficult to know how to manage cancer in the workplace or to know how to support other employees in response to their colleague being diagnosed. Therefore employers also need more support and guidance.

*'Cancer is such an emotive subject. It needs a lot of thought as to how we make this accessible and acceptable to people. Some people can't even look people with cancer in the eye... Sometimes we find it's the managers who have more problems than the person who is coming back to work.'*

**Shaw Trust Manager**

*'The employer has to balance the needs of individuals and the needs of colleagues – if you've only got a small team you may not be able to cope with the demand... SMEs can't provide as much individual support as people need or as much as they would want to. It's those sort of issues we need to look at as a strategy. The employers need support and we need to raise awareness with them.'*

**Shaw Trust Manager**

- 5.21** This guidance need to meet the specific needs of employers.

*'Guidance for employers needs to be demedicalised and concentrate on function not the condition.'*

**OHP**

*'SMEs are run by people who are multi talented individuals. They are the salesman, the managing director, the accountant, the H&S officer and immensely practical and innovative. So if they get the right guidance they will apply it.'*

**OHP**

- 5.22** Some thought also needs to be given as to how best to disseminate any guidance. The best route is likely to be via the employees.

*'If you run a small business the number of times you need to use any guidance might be once every ten or twenty years, so the conduit is the person with cancer. That's how you get to them because they won't pick up on something unless it's relevant to them at that moment.'*

**OHP**

- 5.23** Translating advice into action may also require additional support for all parties involved:

*'It's not just about providing good information and encouragement but also enabling people to make that change. It might be quite sophisticated – coaching the employee but also the line manager. In good case management, as seen in the US or Australia, you get that triangulation between the patient, service provider and workplace, so they work as a unit.'*

**OHP**

## 6. Suggestions for improving rehabilitation provision

- 6.1 All interviewees were also asked for their views on what could be done to improve vocational rehabilitation services for people with cancer. These are summarised below.

### **Raise awareness and increase understanding of the needs of people with cancer**

- 6.2 Planning a return to work for people with cancer is currently not very high on anyone's agenda. Therefore there is a lot of work to be done simply to raise levels of awareness amongst all stakeholders and to ensure that the needs of people with cancer have been well researched and widely disseminated.

*'We may need to educate professionals and people affected by cancer to influence the conversations that people are having.'*

**OHP**

*'At the moment we've just gone through a surge of the profile being raised on end of life care. Maybe it's time to shift that emphasis... maybe we need to be more aware of work rehab issues.'*

**OT**

- 6.3 All health professionals would benefit from training and guidance on the long-term effects of cancer treatment, the likely impact on work and the support people need to overcome these challenges.

*'Health professionals need to be trained to raise this issue with their patients and tell them where they can go to get support.'*

**OT**

*'You could look at developing a GP practice education workshop, to be presented to PCTs, to make the case for addressing this issue... you could also develop a distance-learning pack that practices could work on in their team meetings. It would be good to sell this training and education to GP practices by emphasising the overlap with other conditions.'*

**GP**

*'OHPs would like an evidence based guide on common cancers and standard treatments regimes including basic information like: how common is nausea on this form of chemotherapy? If given symptoms and timescales OHPs can work out occupational advice.'*

**OHP**

*'It would be useful to find out exactly where there are gaps in people's understanding of issues relating to function, prognosis and duration of symptoms like fatigue with different treatment regimens, as this would indicate where there's a need for educational interventions.'*

**OHP**

### **Make returning to work an integral part of cancer care**

- 6.4 This could be achieved by developing new standards of care across cancer services that integrate vocational rehabilitation.

*'So when services are audited against these standards – they will check what advice has been given about work.'*

**Consultant in RM**

- 6.5 It would also help to make returning to work a formal part of health and social care assessments at all stages of the cancer journey.

*'It needs to happen along when you meet people for the first time, to find out whether work is something important for them – but their thoughts may change – so you need to revisit it at a number of points along the way.'*

**CNS**

#### **Raise awareness and increase the use of existing services**

- 6.6 In order for existing OT services to provide vocational rehabilitation, resources would need to be invested in both increasing the capacity of the service and raising awareness of their enhanced role. It would also be important to facilitate joint working between cancer specialists and rehab specialists.
- 6.7 In order for people with cancer to make better use of the services available via Jobcentre Plus, there needs to be stronger signposting and links between the NHS and outside services.

#### **Learn from examples of existing good practice in vocational rehabilitation**

- 6.8 It would be helpful to gather examples of good practice from the UK and other countries and to find ways to share this learning across the cancer networks.

*'You could look at the US system for example and ask what is applicable here, not just to transport the services wholesale, but find out what principles are useful in the UK.'*

**OHP**

#### **Develop and pilot new models of vocational rehabilitation service to reflect different types of need**

- 6.9 This could be achieved by setting up a think tank of a wide range of stakeholders including people with cancer, to work out exactly what needs to be provided along different stages of the patient journey and to think about how best to put these services in place.

- 6.10 Ideas for new models of service include:

- Establishing specialist work rehabilitation therapists to provide an independent source of advice and training for other health professionals, employers and people with cancer.
- Siting OH nurses in GP surgeries, with one nurse shared across a number of practices.

#### **Produce information, tools and practical guides for employers and people with cancer**

- 6.11 Ideas for different types of information and tools include:

- a checklist for patients to assess themselves and make a decision about returning to work that they could share with their employers or HR department.
- guidance for employers on what's feasible and practical to do to support employees with cancer returning to work. This could also helpfully include advice on the employment law duties of employers.

## 7. Recommendations and next steps

**‘Getting people back to work, that is going to become a much bigger issue than it is now - because of cancer survivorship. That’s going to increase by 30% over the next few years, so we are going to have lots and lots of people out there who have had cancer, and the stigma that goes with that, and the anxiety problems. We’ve got to find an approach that looks at helping those people...The more people who survive; the more people are going to need a positive rehab experience’**

**Network AHP Lead**

### **Recommendations to be taken forward**

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| <p><b>7.1</b> Cancer-specific occupational health tools and resources should be developed for health professionals, employers and patients. Macmillan could lead on the development of these, having already developed best practice guidance for employers.</p> <p><b>7.2</b> The Department of Health and Macmillan should work together to explore how health professionals can best support people in returning to work after cancer.</p> <p><b>7.3</b> Stronger links need to be made between Jobcentre Plus and the NHS so that health professionals are better able to signpost patients to DWP employment services. Information and referral triggers for employment and rehabilitation should be built into care pathways. Further consideration is needed of the role information prescriptions could play in this. Return to work advice and support should also be a core element of post-treatment plans.</p> | <p><b>7.4.</b> The lack of capacity in both vocational rehabilitation and occupational health services must be urgently addressed. The Government should explore ways of improving access to rehabilitation services for SMEs and consider whether this is best achieved through a substantial investment in NHS rehabilitation services or whether other models for both funding and providing vocational rehabilitation services should also be developed.</p> <p><b>7.5</b> Based on the findings from this exercise, it may be necessary to develop and pilot a number of new models of vocational rehabilitation service to reflect different types of need. A number of issues require further investigation and consideration:</p> <ul style="list-style-type: none"> <li>• whether there is an optimal point of intervention for people with cancer</li> <li>• whether a cancer occupational health specialism should be developed</li> <li>• what role GPs and nurses should play in supporting a return to work</li> <li>• whether the right NHS levers and incentives are in place to deliver better return to work services</li> </ul> |
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It would also be worth investigating whether a multi-tiered model of support with GP practice staff, cancer doctors, clinical nurse specialists providing general information/advice and rehabilitation specialists (OHPs and OTs) providing specialist support, is the best way to provide a comprehensive service.

- 7.6** Additional research may be useful to strengthen the evidence base and inform thinking on possible new models of service delivery. In particular, it is worth reviewing:
- What we can learn from existing examples of good practice.
  - The experiences of occupational health and vocational rehabilitation services in other countries.
  - Rehabilitation provision in the devolved health administrations in Scotland, Wales and Northern Ireland.
- 7.7.** Further research is required to look at whether people with cancer (particularly those still in employment) have adequate access to return to work support through Jobcentre Plus. This research should also look at whether the specific needs of people with cancer using Jobcentre Plus employment services are being met.

### **Next steps - Macmillan's Working through Cancer campaign**

- 7.8** Macmillan's Working through Cancer campaign aims to secure fair treatment for people affected by cancer in the workplace. Improving occupational health and vocational rehabilitation provision for people with cancer is central to meeting this aim. This scoping study will be used as a basis for commissioning further research, developing policy and devising and piloting new models of service provision to address gaps.
- 7.9** Macmillan has embarked on an ambitious programme of work to tackle this agenda. Over the next five years, this includes:
- Highlighting the lack of advice and support currently available to people diagnosed with cancer and their employers.
  - Carrying out an extensive programme of research into the issues faced by people with cancer at work.
  - Developing a range of support for employers and managers and providing information and advice for employees to help them make informed decisions about their health and work.

- Encouraging employers to adopt the principles of Macmillan’s best practice guidance, and to provide feedback to help improve the guidance.
- Encouraging people affected by cancer in the workplace to share their experiences, good or bad, to help them improve the advice and support currently available.
- Establishing an expert advisory panel, consisting of employment experts, employers and opinion formers and influencers from the world of business, work, health and social policy to inform policy, service development and campaigning.
- Investing significantly in developing and piloting new models of service provision to identify the most effective ways to support people with cancer as they remain in or return to work.

**Kristina Staley**  
**February 2008**

Kristina Staley is a freelance Policy Analyst. After gaining her PhD from Cambridge University, and working as a post-doctoral fellow in the USA, she moved into health and science policy, working in the Public Health Department at The King's Fund and Sussex University's Science Policy Research Unit. She has worked on a wide range of Macmillan projects for over five years.

## Appendix 1: List of interviewees

Many thanks to the following people who very generously gave their time and expertise to help with this project.

**Andrea Blaney**, Macmillan OT

**Charles Campion-Smith**, GP & Macmillan GP advisor

**Sharon Cavanagh**, Macmillan Therapy Team Manager, Occupational Therapist

**Clive Cook**, Pathways to Work Support Manager

**Andrew Frank**, Chair of the British Society of Rehabilitation Vocational Rehabilitation Special Interest Group in Vocational Rehabilitation and Consultant in Rehabilitation Medicine and Rheumatology

**Derek French**, Pathways to Work Project Manager at the Department for Work and Pensions

**Debbie Hamilton**, Condition Management Programme Project Manager and Clinical Lead

**Julie McKenzie**, Shaw Trust Manager

**Emma Sweeney**, Macmillan Clinical Nurse Specialist

**Jackie Turnpenney**, Network AHP Lead

**Stuart Whitaker**, Senior Lecturer in Occupational Health and Specialist Practitioner in Occupational Health Nursing

**Nerys Williams**, Consultant Occupational Physician and Principal Occupational Physician at the Department for Work and Pensions

**Philip Wynn**, Senior Occupational Health Physician

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. One in three of us will get cancer. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

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