

Disability Living Allowance reform

Macmillan's response

Key points

- Cancer treatment results in a sudden onset of daily living and/or mobility needs.
- The need for help with daily living and getting around can start immediately and escalate rapidly.
- For increasing numbers of people, cancer is a long-term condition.
- Extending the qualifying period to six months will penalise many cancer patients at a time when they are most in need of support.
- Where mobility and/or daily living supports needs arise suddenly and are likely to continue for twelve months, the qualifying period should be waived.

Introduction

1.1 Macmillan welcomes the opportunity to respond to Government's review of Disability Living Allowance (DLA), particularly as disability benefits will become increasingly important to people living with cancer. Currently, there are two million people living with and beyond cancer in UK and this figure is rising by three per cent each year.¹

1.2 As survival rates in cancer continue to improve, people diagnosed with cancer will increasingly join people with other long term conditions in living with ongoing support needs. People living with and beyond cancer have serious physical, emotional, social problems that need addressing. Additionally, as is acknowledged in the consultation document, many aspects of DLA as it stands do not work well for people living with cancer. A study exploring the barriers to DLA encountered by cancer patients found that:²

¹ Maddams J, et al. (2009) Cancer prevalence in the United Kingdom: estimates for 2008 British Journal of Cancer 2009. 101: 541-547

² Macmillan Cancer Relief (May 2005) Access Denied: Benefits Advisers' Perceptions of the problems cancer patients face when claiming Disability Living Allowance and Attendance Allowance

- Patients find it difficult to complete the DLA application form, finding it lengthy, repetitive, ambiguous and irrelevant to their circumstances and the specific needs arising from living with cancer.
- Ignorance about the symptoms of cancer and its treatment may make it difficult for Department of Work and Pensions (DWP) Decision Makers, who have not received training on these issues, to assess cancer patients' entitlement to DLA or Attendance Allowance (AA).
- DWP decision-making is inconsistent, particularly when patients have a disease that is thought to be curable. This can lead to patients' feeling a sense of frustration and injustice.

1.3 Given this, we support Government's ambition to create a disability benefit that is easier to understand than DLA and results in a better service for disabled people.

1.4 We also support Government's goal of continuing to support disabled people in need. However, we believe the extension of the qualifying period from three to six months will leave people diagnosed with cancer stranded without vital support at the most crucial time.

1.5 In gathering evidence to inform this response, we conducted two focus groups: one with people affected by cancer and another with occupational therapists with a cancer specialism.³ In addition, we consulted with our specialist team of Welfare Right Advisers.

What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?

2.1 There are a number of symptoms that are common to many people living with cancer. These include pain, fatigue and mental health issues. To ensure that these debilitating factors are always taken into account when assessing for PIP, the claim form should include questions explicitly designed to elicit information on experience of these common factors, their severity and their frequency of occurrence. The form should be designed such that ability to repeatedly undertake daily activities/mobility activities is assessed. Additionally, guidance provided to Decision Makers should explicitly draw their attention to these factors. Both the claim form and the Decision Makers' guidance should reflect the need to assess the fluctuating nature of debilitating factors.

Pain

2.2 Pain is the first symptom of cancer in 20 - 50 per cent of all cancer patients. 75 - 90 per cent of advanced or terminal cancer patients experience chronic pain syndromes related to chemotherapy, failed treatment, and/or tumour

³ RS Consulting/Macmillan Cancer Support (Jan 2011) qualitative research amongst people living with cancer and, separately, occupational therapists with a cancer specialism. Online discussion groups with both groups

progression.⁴ The most commonly diagnosed cancers - lung, prostate, and breast cancers often move to the bone, and in advanced states, they are associated with bone destruction and eventual bone fracture causing incapacitating pain and limited or total loss of daily activity.⁵

2.3 Pain limits daily activity in 41 per cent of patients reporting mild to moderate pain and in 94 per cent of patients reporting moderate to severe pain. Pain leads to a greatly diminished quality of life in these patients.⁶ Pain from bone destruction is very difficult to control, and it represents one of the most serious and highly debilitating cancer related events.⁷ Chronic pain can make it hard to do everyday things such as bathing, shopping, cooking, sleeping and eating.⁸

2.4 People living with cancer can experience a range of symptoms in addition to pain, depending on the type of cancer they are diagnosed with. For example, someone with bowel cancer may experience frequent diarrhoea, someone with leukaemia will have low immunity and experience physical weakness, whilst someone with prostate cancer will need to pass urine more frequently than usual, especially at night and so experience sleep deprivation. However, the main debilitating consequences related to cancer are as a result of toxic and aggressive treatment.

2.5 Opioids are currently the most effective and most appropriate treatment for moderate to severe cancer-induced pain, and they remain the best front-line treatment for cancer pain patients. However, patients need to be monitored and cared for closely due to potential adverse effects of opioids.⁹

2.6 Adverse effects of opioids in the short-term can include dizziness, nausea, vomiting, drowsiness and confusion. Problems associated with longer-term use of opioid drugs include constipation, itching, weight gain, lack of sex drive and difficulty breathing at night. Taking opioids over months or years can result in reduced fertility, low sex drive, irregular periods, erectile dysfunction, reduced ability to fight infection and increased levels of pain.¹⁰

⁴ Ballantyne J et al (2010) Opioids in cancer pain: New Consideration. International association for the study of pain

⁵ Ballantyne J et al (2010) Opioids in cancer pain: New Considerations International association for the study of pain

⁶ Ballantyne J et al (2010) Opioids in cancer pain: New Considerations International association for the study of pain

⁷ Ballantyne J et al (2010) Opioids in cancer pain: New Considerations International association for the study of pain

⁸ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/pain/types-and-causes-of-cancer-pain

⁹ Ballantyne J et al (2010) Opioids in cancer pain: New Considerations. International association for the study of pain

¹⁰ The British Pain Society (January 2010) The British Pain Society's Opioids for persistent pain: Information for patients

Fatigue

2.7 Cancer-related fatigue is one of the most common side effects of cancer and its treatment.¹¹ Fatigue is not merely passing tiredness, but is experienced as a chronic and debilitating consequence of the treatment of cancer. Fatigue can be physical or psychological. Where a person living with cancer experiences physical fatigue, they feel physically weak and lack energy. People living with cancer who experience psychological fatigue, find it difficult to concentrate, find problem-solving difficult and lack motivation.

2.8 Fatigue is not predictable by tumour type, treatment, or stage of illness. Usually, it comes on suddenly, does not result from activity or exertion, and is not relieved by rest or sleep. It is often described as 'paralysing' and can continue even after treatment is complete.¹² Fatigue affects between 70 - 90 per cent of people with cancer. Many people with cancer say that it is the most disruptive side effect of all.¹³ Over 90 per cent of people with cancer who experience from fatigue said fatigue stopped them leading a normal life.¹³

Problems eating/mouth problems

2.9 One in three people who have chemotherapy or radiotherapy to the head and neck will develop mouth problems. These problems can become serious and affect daily life. They can make eating, talking and swallowing very difficult. If someone living with cancer can't eat comfortably it can reduce their appetite, which may result in weight loss.¹⁴

2.10 Mouth ulcers are most likely to develop about five to ten days after chemotherapy starts. They start a bit later with radiotherapy to the mouth.¹⁵ Sometimes mouth ulcers can get so bad that the doctor may decide to lower the dose of the cancer drug or stop treatment altogether until the ulcers clear up. This can be very distressing as patients want to get the treatment over with as soon as possible.

2.11 It can take a long time (six months or more) for saliva production to go back to normal after radiotherapy treatment. If you've had radiotherapy directly to your salivary glands, they may never completely recover.¹⁶

Restricted movement

2.12 Swelling of the arm due to lymphoedema can occur after breast surgery. This causes stiffness and restricted movement of the arm. This in turn can make daily activities like dressing difficult. Once lymphoedema occurs it can

¹¹ www.medicinenet.com/cancer_fatigue/article.htm

¹² www.medicinenet.com/cancer_fatigue/article.htm

¹³ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/fatigue/what-is-cancer-fatigue

¹⁴ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/mouth/types-and-causes-of-mouth-problems

¹⁵ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/mouth/types-and-causes-of-mouth-problems

¹⁶ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/mouth/types-and-causes-of-mouth-problems

never be completely cured. Additionally, people living with cancer who develop lymphoedema following breast surgery, the arm and hand are more prone to infection.

Anxiety and depression

- 2.13 Around the time of a diagnosis of cancer, approximately 50 per cent of patients experience levels of anxiety and depression severe enough to affect their quality of life adversely.¹⁷ Although psychological issues are more common in the first year after treatment¹⁸ one third of patients continue to report significant levels of distress well after treatment has been completed.¹⁹ Even ten years on, over half (54 per cent) still experience at least one psychological issue.²⁰ Macmillan's 'Worried Sick' report found that three quarters (75 per cent) of people with cancer experience anxiety and half (49 per cent) experience depression.²¹
- 2.14 During cancer treatment and after it ends, it is not unusual to have persistent feelings of depression or anxiety. These symptoms occur in almost a third (about 30 per cent) of patients and survivors. Where people living with cancer have a past history of depression or anxiety, their risk of re-developing the symptoms is higher.²²

Jen, 45, from Maidenhead; diagnosed with breast cancer 2004, aged 40, treated with surgery, chemotherapy and radiotherapy.

"After my treatment finished, I felt like a wet rag. Emotionally I was scared and truly lost. People think it will take a month or two for you to recover; there is an expectation that you will be back to your old self, but the reality is several years. I felt I had to put a mask on in order to be the loveable, funny, Jen that people liked to be with.

I lost a couple of really good friends because of the after-effects. One of them said 'Cancer changes people'. I really felt I was being punished for having this dreadful illness. That first year, I had the worst Christmas ever and seriously considered taking my own life. I was living in a constant anxiety attack.

Physically I have been affected too. The chemotherapy has thinned my bones and I have got osteoporosis in my spine and my hip, the treatment for which gives me blisters in my mouth. I have developed hearing problems including tinnitus and have to wear hearing aids."²³

¹⁷ National Institute of clinical excellence. (2004) Supportive and Palliative care: The manual NICE

¹⁸ Macmillan Cancer Support (2009) It's no life. Living with the long term effects of cancer Macmillan Cancer Support

¹⁹ Carlson L et al. (2004) 'High levels of untreated distress and fatigue in cancer patient' British Journal of Cancer

²⁰ Macmillan Cancer Support (2009) It's no life. Living with the long term effects of cancer Macmillan Cancer Support

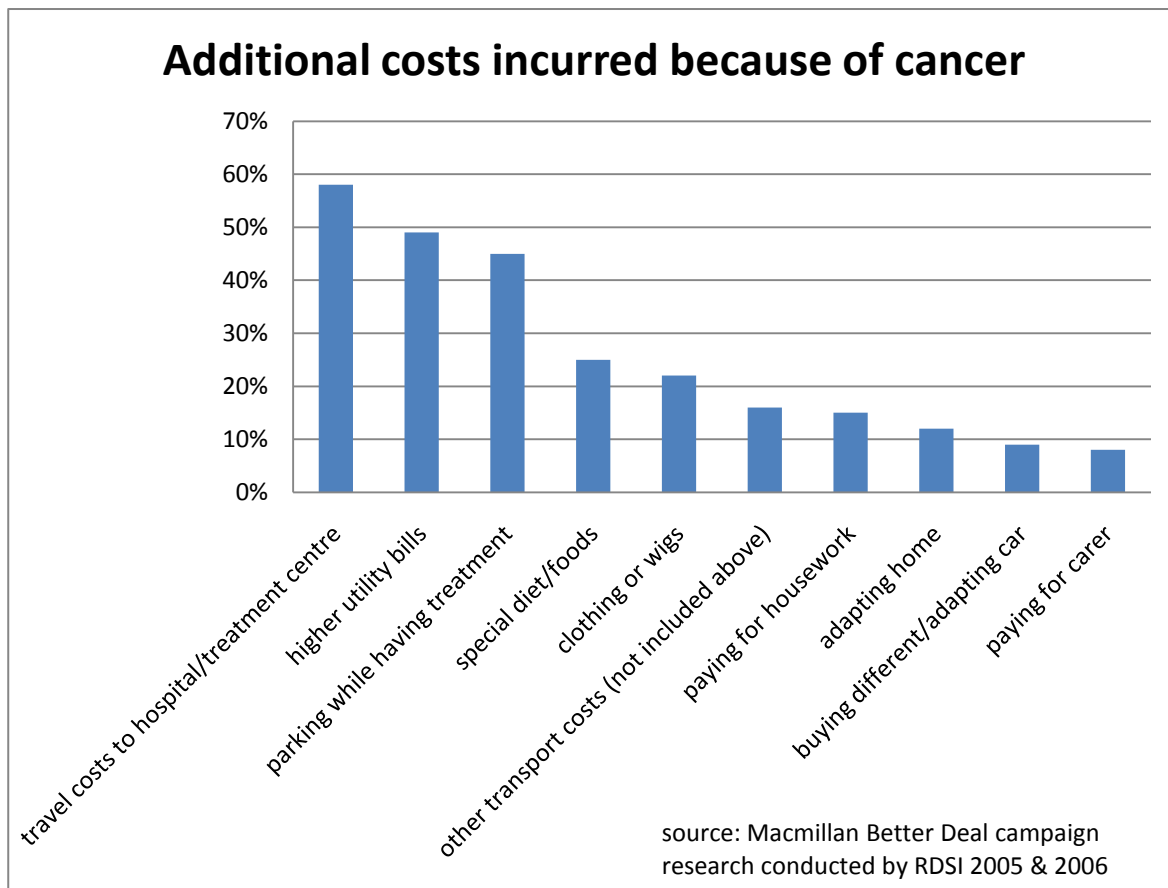
²¹ Opinion Leader Research (April 2006) Worried Sick: the emotional impact of cancer Macmillan Cancer Support

²² <http://north.sanfordhealth.org/medicalservices/specialties/cancer/sideeffects/depression.aspx>

²³ Macmillan Cancer Support (2008) It's no Life: Living with the long term effects of cancer

What are the main extra costs that disabled people face?

The graph below shows the key costs incurred by people living with cancer.²⁴



3.1 Qualitative research amongst people living with cancer conducted for Macmillan Cancer Support found that people living with cancer experience a wide range of additional costs (and often continue to face) as a result of their cancer and its treatment:

- Hospital car parking and transport costs
- Heating bills due to feeling the cold more
- More expensive diet
- New clothes and shoes
- Aids and adaptations such as stair rails
- Wigs, shoe inserts (orthotics)²⁵

²⁴ 1137 interviews were conducted with cancer patients and carers 29/11/05 – 22/12/05 & 03/01/06 – 22/02/06

²⁵ RS Consulting/Macmillan Cancer Support (February 2011) online qualitative research amongst people living with cancer

3.2 Many cancer patients experience reduced immunity as a result of treatment. As a consequence of the increased risk of infection, people living with cancer are unable to safely use public transport. This results in increased travel costs, as cancer patients rely on taxis to get around.

3.3 People living with cancer can have difficulty regulating their body temperature or can be subject to greater feelings of cold as a result of decreased mobility, weight loss and/or hair loss. This in turn results in increased heating costs. Our research has shown that six out of ten people with cancer have had higher energy bills since diagnosis.²⁶

3.4 One in three people who have chemotherapy or radiotherapy to the head and neck will develop mouth problems. These problems are can so serious as to affect daily life. They can make eating, talking and swallowing very difficult. Inability to eat comfortably can reduce appetite and result in loss of weight. Some treatments may also mean that cancer patients receiving those treatments have to maintain special diets.

“My shopping bills increased as my diet became more restricted. Instead of milk and dairy products, for instance, I now take soya milk and soya products. I also purchase various dietary supplements and Ayurvedic tonics in order to boost my immune system and general health.” (Female, Breast Cancer, 4 years ago)

3.5 People living with cancer can also experience swelling or changed body shape due to either lymphedema or taking steroids. Additionally, they may experience weight loss associated with treatment, or changed body shape as a result of surgery. People living with cancer will have to buy new clothes to replace those that no longer fit.

“Some clothes that I used to wear before my cancer have had to be discarded because I can't put them on, and some are clothes that hurt my chest if I wear them. I used to wear tiny tight sari-blouses - I don't any more. I wear t-shirts or pullovers instead, even on the occasions I'm wearing a sari - and yes, it looks odd.” (Female, Breast Cancer, 4 years ago)

How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?

4.1 Adverse effects of treatment are the main problems and result in a rapid escalation of needs. At a general level, a cancer patient, particularly during the acute stage of initial treatment, can experience challenges and problems in all areas of life:

- Getting out of the home – to the shops and local amenities
- Personal care – washing, going to the toilet

²⁶ Macmillan Cancer Support (June 2009) online survey of 974 people living with cancer. Survey results are unweighted

- Domestic tasks – cooking, cleaning, caring responsibilities
- Employment & education – unable to continue working or studying
- In addition to physical side-effects such as pain and nausea that can limit patient’s activities, fatigue is mentioned as a common problem.²⁷

“I couldn’t do very much at all as walking and moving was so painful; also sitting My first treatment was laser which was a total disaster and left me with severe scarring and nerve pain.” (Female, Gynaecological Cancer, 10 years ago)

“Once you’ve had chemo you are totally worn out, then I was supposed to have a month break then radio. It didn’t happen and I had two days! It’s just total wipe out.” (Female, non-Hodgkin’s bone cancer, 9 years ago)

4.2A particular issue raised by those who received chemotherapy is ‘chemo brain’ – described by people living with cancer as a negative impact on their memory and cognitive ability, compromising mental functionality to the extent that they are unable to do everyday tasks or multitask.²⁸

“Lapses of memory, can’t think of the word you need, repeating questions three times in the same number of minutes I have post-it pads everywhere in the house, my bag, by the bed, in the kitchen, if I don’t write it down, no matter how small (like get milk!), then it won’t get done!” (Female, non-Hodgkin’s bone cancer, 9 years ago)

“I can’t multi task any more even to the extent of cooking and talking at the same time, can’t get words sometimes, go very slowly, just can’t think straight sometimes ... it’s hard to explain.” (Female, Breast Cancer, 7 years ago)

Debilitating effects of cancer and/or its treatment likely to last for the longer term

4.3 Government proposes that PIP will only be paid to people whose health condition or impairment ‘*must be expected* to last for a minimum of 12 months’ (emphasis added).²⁹ This contrasts with the Equality Act 2010 definition of long term: ‘where the total period for which it lasts, from the time of the first onset, is *likely* to be at least 12 months’ (emphasis added).³⁰ We would welcome an assurance that it is not Government’s intention to set the threshold for what constitutes ‘long-term’ in relation to PIP, higher than that which applies in equality law.

²⁷ RS Consulting/Macmillan Cancer Support (February 2011) online qualitative research amongst occupational therapists with a cancer specialism

²⁸ RS Consulting/Macmillan Cancer Support (February 2011) online qualitative research amongst occupational therapists with a cancer specialism

²⁹ DWP (December 2010) Disability Living Allowance reform Cm 7984

³⁰ Office for Disability Issues (2010) Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability

4.4 Additionally, the Equality Act guidance suggests that in assessing ‘long-term’, account should also be taken of both the typical length of time a debilitating impairment might last for and any relevant factors specific to the person living with cancer - for example, general state of health or age.³¹ The guidance goes on to say that ‘conditions with effects which recur only sporadically or for short periods can still qualify as impairments for the purposes of the Act, in respect of the meaning of ‘long-term’.³² We take Government’s referral to the Equality Act guidance as welcome continuing recognition that fluctuating conditions can be long-term, despite a person not experiencing relevant symptoms at all times.

4.5 This is particularly (but not exclusively) the case for people who are living with cancer for an extended number of years and for whom there is no ‘cure’. All participants in our focus group research cited on-going fatigue and exhaustion as a significant problem that severely limits their ability to engage with daily living activities. People living with and beyond cancer report feeling ‘old’ and far older than they really are.

“It’s now over five years since treatment finished and I am still fatigued and brain not working as well as it did ... fatigue was worst at the end of treatment [but] is a little better now but I still have chemo brain ... I also have problems with insomnia, anxiety and depression. I have to rest frequently which means I can do most things so long as I pace myself and do things sitting down when I can ... the frustration of not being who I was leaves me depressed quite often. Though I am now adjusting to a new normal which is effectively retirement - I haven’t got the energy to do more than day to day activities - ie no energy for work; just domestic stuff uses up all my energy.” (Female, Breast Cancer, 7 years ago)

4.6 Alongside this, there are also clear emotional and psychological impacts that affect how people living with cancer are able to interact with others and engage in daily life. Often, the realisation that the physical pain, discomfort and exhaustion are long-term conditions itself leads to increased mental health issues such as anxiety and depression. People express the sentiment that they have lost their sense of ‘self’ and are unable to ‘operate’ as they once did. This is also associated with on-going ‘chemo brain’.

“I was always outgoing, a go getter, ‘can do’ sort of bod. I see it occasionally but feel I’ve lost a big part of ‘me’. I’m isolated and avoid social contact ... I feel the long term impact has taken me by surprise, pain in bones, headaches, fatigue, frustration and not feeling fit and able to function as I did pre-diagnosis causes depression.” (Female, Breast Cancer, 5 years ago)

³¹ Office for Disability Issues (2010) Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability

³² Office for Disability Issues (2010) Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability.

4.7 We believe that cancer patients should be entitled to apply for PIP as soon as their need for support arises and not be asked to wait six months before being allowed to do so. We recognise that Government wants to move away from automatic entitlement on the basis of condition. We agree that diagnosis should not determine whether or not someone receives PIP. Instead, we believe that:

- a) where treatment received is such that a sudden onset of daily living and/or mobility supports needs will arise and
- b) will be likely to continue for the following twelve months,
- c) the person receiving that treatment should be permitted to apply for PIP at the point at which their treatment begins.

How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?

5.1 We are concerned about the potential risk of modelling the new assessment on the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA). People living with cancer have told us that the WCA is not thorough enough, does not allow them to properly explain the problems they face and that the assessing doctors are not always familiar with these difficulties or problems.³³ Inadequate assessment then results in the wrong decisions being made about benefit entitlement. The experiences of cancer patients echo the findings from the Harrington review of the WCA. In his review last year, Professor Harrington identified a number of significant shortcomings with the WCA, which included:

- Claimants' interactions with Atos are often impersonal, mechanistic and lack clarity.
- Some conditions are more difficult to assess than others. This appears to be the case with fluctuating conditions. As a result, some of the descriptors used in the assessment may not adequately measure or reflect the full impact of such conditions on the individual's capability for work.

5.2 We would welcome assurance from Government that the following core principles will inform the development of the PIP assessment tool and its application:

- PIP assessments should be carried out by appropriately trained healthcare practitioners with the expertise and knowledge to carry out a comprehensive assessment.
- Adequate time is allowed for a comprehensive assessment of both physical and mental health issues.³⁴

³³ Mitchell J (2009) Failed by the System: Why the Employment and Support Allowance isn't working for people living with cancer Macmillan Cancer Support and Citizens Advice

³⁴ When we spoke to Occupational Therapists (OTs) with a cancer specialism, they told us it is not possible to carry out a full assessment of a person's physical and mental health functionality in less than two hours.

- Appropriate supporting evidence should be sought. This evidence is given equal weight to the face-to-face PIP assessment findings by DWP Decision Makers.
- PIP descriptors should be designed in such a way as to capture the fluctuating nature of the impacts of impairment by, for example, including prompts about frequency and severity of effect.
- Patients will be encouraged to keep a diary of the impacts of their impairments and the frequency and severity of those impacts. These diaries are given equal weight to the face-to-face PIP assessment findings by DWP Decision Makers.

5.3 Our Welfare Rights Advisers tell us that DWP Decision Makers will often only look at the length of treatment when deciding eligibility for DLA and do not take after effects into consideration. As detailed above, it is often the after effects of treatment that debilitates people living with cancer over the long term. We would want guidance issued to accompany the PIP to make it explicit that assessment of the longevity of debilitation should take in to account actual and expected long-term effects of treatment, as well as cancer itself.

5.4 We would be happy to discuss how Macmillan might support Government in designing a PIP assessment tool that captures fully claimants' physical and mental health limitations.

5.5 Additionally, because of the highly complex nature of cancer, we believe that assessments of PIP applications from people living with cancer should only be carried out by Decision Makers trained to at least higher level PIDMA accreditation.

Should the assessment of a disabled person's ability take into account any aids and adaptations they use?

- What aids and adaptations should be included?
- Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?

6.1 Assessments should only take into account aids and adaptations that a person already has, could reasonably obtain and will be able to keep on an unconditional basis.

How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:

- How could we make the claim form easier to fill in?
- How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?

7.1 We, like Government, are keen that those who need support with daily living and/or mobility needs get that support when they need it and for as long as they continue to need it. However, at the moment, cancer patients lack information and specialist advice on disability benefits, and consequently misunderstand the purpose of DLA, the criteria for assessment and process for claiming.

7.2 Research suggests that inconsistent and unclear information about the purpose of DLA and unclear, inconsistently applied eligibility criteria and rules of process are the cause of claimant apprehension about moving into work.³⁵ As noted in the consultation document, DLA is not an out-of-work benefit and we welcome the assurance that PIP will keep that status. In order to ensure that this is understood by people living with cancer, those that advise them, including health care practitioners and those that administer the benefit, Government should ensure the provision of clear and consistent information about what PIP is for.

7.3 Last year's Cancer Patient Experience Survey found that only 50% of patients who said it was necessary had received information about financial help.³⁶ In addition, there have been reports from many people living with cancer of frustration at being unaware of the support available until late in their illness. Information about PIP should feature in the written care plans cancer patients should be offered by their healthcare practitioner and/or be provided an Information Prescription.

What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?

8.1 Decision Makers need more evidence from a wider range of professionals in order to make a properly informed decision. Evidence should not just come from GPs. Additional information provided by GPs will often only talk about the cancer and not the after effects. In many cases, Cancer Nurse Specialists, physiotherapists, occupational therapists and other health and social care practitioners will be more appropriate. Very often, the patient will be best

³⁵ Disability Living Allowance and work: Exploratory research and evidence review (2010) DWP Research Report No. 648.

³⁶ Quality Health (December 2010) National Cancer Patient Experience Survey Programme 2010 National Survey Report Department of Health

placed to identify the healthcare professionals best able to provide additional relevant information.

8.2 The tool for eliciting the necessary information from healthcare practitioners should be better designed, such that the information provider is prompted to provide a comprehensive written assessment of all relevant factors. Macmillan would welcome the opportunity to work with Government to design cancer-specific aspects of any such tool.

8.3 Reports provided by healthcare practitioners should be routinely discussed with claimants to ensure that all aspects of a claimant's functional limitations are taken into account.

An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.

- What benefits or difficulties might this bring?
- Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?

9.1 Many people living with cancer will experience debilitating fatigue, pain and reduced immunity to infection. We believe that where people living with cancer are experiencing these symptoms, they should not be required to attend a medical as a matter of routine. Additionally, cancer patients still in treatment may be required to attend a hospital or treatment centre on a daily basis or be so debilitated by that treatment that a requirement to attend an additional PIP face-to-face consultation would be unreasonable.

How should the reviews be carried out? For example:

- What evidence and/or criteria should be used to set the frequency of reviews?
- Should there be different types of review depending on the needs of the individual and their impairment/condition?

10.1 We support Government's plan to build on the current case review process already in place for DLA, to ensure claimants are getting the right rate of benefit. We believe the frequency of assessments should be determined by the typical length of time a debilitating impairment might last for and any relevant factors specific to the person living with cancer - for example, general state of health or age.³⁷

³⁷ Office for Disability Issues (2010) Equality Act 2010 Guidance: Guidance on matters to be taken into account in determining questions relating to the definition of disability

10.2 Where a claimant's condition is unlikely to improve over time, such as is the case for lung cancer, the review should consist of a written report, provided by a relevant healthcare practitioner, confirming that the claimant's functional limitations have not improved. Where this cannot be confirmed, the review should include a face-to-face assessment of the claimant's functionality.

The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?

11.1 Current guidance on what constitutes a change in circumstances is unclear. We believe written advice should be provided to claimants indicating a change-in-circumstances trigger, for example, a new treatment. A change in circumstances should have to be shown over a period of time, for example, three months, to distinguish it from a fluctuation.

11.2 We would welcome an assurance from Government that PIP will not include any new sanctions.

What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?

12.1 People should be provided with a written explanation of what PIP is for and the fact that it is not an out-of-work benefit. They should also be advised of where they can access support with and advice on their claim. Additionally, advice on what claimants can do in the event of their claim being unsuccessful should be provided. Advice on other benefits that could be claimed should also be made available, as should advice on benefits that people getting PIP are passported to.

Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?

13.1 We agree that appropriate and accessible advice and support should be made available to claimants. However, we would object strongly to the introduction of conditionality into the provision of support for mobility and/or daily living needs. As far as we understand it, the very purpose of PIP will be to provide a claimant with funds to access support needed to overcome disability-related barriers. There is a built-in incentive for claimants to seek and

act on information and access support that enhances their quality of life. Given this, it is unclear why Government sees a need to require claimants to do this.

- 13.2 We would welcome an assurance from Government that PIP will not include any new sanction regime. More specifically we would welcome an assurance that PIP recipients would not risk losing support if they did not access support services/advice they were signposted to and that PIP award decisions will not be influenced by the availability of local social service provision.

What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?

- 14.1 Removing passported benefits linked to DLA would likely increase cost, complexity, bureaucracy and burden on claimants as application and assessment processes would have to be separated.
- 14.2 Awareness amongst people living with cancer of other available sources of support could be a problem as it would become less clear what benefits they would be eligible for.

What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?

- 15.1 DLA and ESA applications processes should be kept separate in recognition that they are for different purposes/need.
- 15.2 If the application processes are combined there is a risk that a decision not to award one benefit could bias the decision about the other benefit. This already happens to a degree, as often reports that lead to a refusal of ESA will be used to assess a DLA application.

Is there anything else you would like to tell us about the proposals in this public consultation?

Special rules

- 16.1 If migration from DLA to PIP takes place within the existing three-year award period, claimants subject to special rules should be migrated automatically and only assessed again when the three year-period elapses.
- 16.2 It is essential that patients who are terminally are identified quickly. We would like the Special Rules gateway to reflect current best practice in palliative care. It is widely accepted within the palliative care sector that the surprise - would you be surprised if their patient died within the next six months – is a more effective tool for identifying terminal illness than asking how long a

patient is expected to survive.³⁸ We would be happy to work with Government to explore how the surprise question can be built into the assessment process.

Passported benefits

16.3 The proposals do not make it clear how or if eligibility for Carer's Allowance will be established within PIP. This needs to be clarified in order to assess the potential impact on carers of these proposed changes to DLA and the corresponding impact on their ability to care for ill or disabled relatives.

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³⁸ Barclay S & Maher J (2010) 'Having the difficult conversations about the end of life' BMJ 341:c4862 doi: 10.1136/bmj.c4862