BENEFITS ADVISERS’ PERCEPTIONS OF THE PROBLEMS CANCER PATIENTS FACE WHEN CLAIMING DISABILITY LIVING ALLOWANCE AND ATTENDANCE ALLOWANCE.

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Executive Summary

This report presents the findings of a study to explore the experiences of cancer patients when claiming Disability Living Allowance (DLA) and Attendance Allowance (AA), and the problems posed by the rules governing the eligibility criteria for these benefits, through the eyes of specialist benefits advisers in the UK.

Background

In 2004, Macmillan Cancer Relief launched its Better Deal campaign to highlight the burdening costs of cancer and the millions of pounds of unclaimed benefit that cancer patients may be entitled to. Studies show that there is regional variation in terminally ill cancer patients’ take-up of Disability Living Allowance and Attendance Allowance.

There are a number of reasons for this, some of which are associated with the unique impact of cancer and its treatment, and the criteria that govern eligibility to the benefits. In short, cancer does not fit the disability benefits rules, putting patients at the risk of financial hardship and adding to the huge emotional strain experienced by many, particularly at the end of their lives.

To address these problems Macmillan is calling on the Government to:

- Ensure that all cancer patients are offered specialist benefit advice at diagnosis
- Waive the three and six month qualifying periods for cancer patients claiming DLA and AA
- Allow hospital in-patients to keep their DLA or AA for 52 weeks
- Scrap the 28-day linking rule
- Change the definition of terminal illness from six to 12 months.

This study was commissioned by Macmillan Cancer Relief to build further understanding of the barriers faced by cancer patients trying to access DLA and AA. It provides benefit advisers’ suggestions for making the DLA/AA benefit system fairer for cancer patients, and provides evidence to support Macmillan’s calls to Government to overhaul the qualifying tests for DLA and AA, and the rules relating to hospital in-patients and the Special Rules for terminal illness.

Methods

Structured telephone interviews were given by 17 specialist benefits advisers, working in Macmillan-funded projects funded which provide benefits advice to cancer patients in England, Scotland and Wales.

Questions explored advisers’ views and experiences of the challenges faced by cancer patients when claiming DLA and AA, and examined aspects of the claims process known from anecdotal evidence to pose particular problems, for example the qualifying tests and rules relating to terminal illness and in-patient care.
Key findings

Knowledge and understanding of DLA and AA:
- Cancer patients lack information and specialist advice on disability benefits, and misunderstand the purpose of DLA/AA, the criteria for assessment and process for claiming.
- Health professionals can be confused about the purpose of the benefits and the tests used to assess eligibility. This may deter them from providing the Department for Work and Pensions (DWP) with information to support their patients’ claims.

Problems with the DLA and AA qualifying conditions:

Retrospective and prospective tests
- Cancer patients find it difficult to meet the eligibility criteria for DLA and AA. Patients with ‘silent’ or ‘sudden’ cancers such as breast cancer, whose disease emerges unexpectedly with few debilitating symptoms before diagnosis and treatment, may have unpredictable care and mobility needs, making it difficult for them to meet both retrospective and prospective qualifying tests for DLA. These patients often have needs that are not considered debilitating enough to warrant an award.
- People who develop progressive symptoms, but delay claiming until they have been diagnosed, may find it easier to meet the retrospective tests, but can also miss out on benefits because claims are not backdated to the time when patients first needed care or support.
- The six-month retrospective test for AA is more difficult for elderly cancer patients to meet, although those with pre-existing health problems are more likely to satisfy the qualifying test.
- Cancer patients find it difficult to predict their future care and mobility needs, meaning they are less likely than people from other disease groups to meet the six-month prospective test for DLA. This is because:
  - Doctors can’t give accurate information about a patient’s prognosis and future care needs. They may not be the best judge of their patient’s needs or the effects of treatment, since they see them for the most part in a hospital or practice environment
  - Doctors may want to believe that their patients will recover quickly and give an overly optimistic view that jeopardises claimants’ chances of meeting the prospective test.

Problems with patients accessing DLA or AA can also affect their entitlement to other benefits, such as Carer’s Allowance and additional premiums or elements within Income Support, Pension Credit, Housing Benefit and Council Tax Benefit. This can cause severe financial difficulties, particularly for patients who depend on state benefits.

Problems with the claims process:

Application form
- 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.
DWP decision-making

- Ignorance about the symptoms of cancer and its treatment may make it difficult for non-medically trained DWP decision-makers to assess cancer patients’ entitlement to DLA or AA.

- DWP decision-making is inconsistent, particularly when patients have a disease that is thought to be curable. This can lead to patients’ sense of frustration and injustice.

- Delays in decisions about claims made under the Special Rules for terminal illness may arise because decision-makers, on the advice of DWP medical officers, reject medical evidence from the patient’s doctor.

Physical and emotional impact

- The physical and emotional impact of cancer and its treatment can make it difficult for patients to cope with the stress of applying for DLA or AA.

- Patients and their families experience hardship and anxiety caused by delays in the processing of their DLA/AA claims and other linked benefits, such as Carer’s Allowance and additional premium/elements with means-tested benefits and tax credits.

Hospital in-patient rules

- The in-patient rules can cause considerable difficulty for cancer patients. Cancer patients are at a disadvantage to other patients, as they are often required to go into hospital for frequent periods of chemotherapy or radiotherapy. Whatever the pattern and length of hospital stay, patients quickly accrue the 28-day limit and can lose DLA and other benefits linked to it.

- Having treatment or care as an in-patient can be a very costly experience for many cancer patients, who incur additional costs while in hospital. This happens at a time when the patient is often unable to work and may have no additional source of income.

- Although in-patient care is provided by the state, patients and their families incur a range of additional costs which are not met by the NHS. These include family travel and parking costs, special foods, TV rental charges, phone calls and reading material.

- The loss of benefits can push low-income patients and their families into financial crisis, leading to debt and the threat of eviction. People who live alone and have no other source of income are also particularly disadvantaged by a loss of DLA and AA. Financial difficulties, worsened by the loss of benefit, can add to the stress and anxiety felt by many patients and their families at a time when their energies are needed to cope with their disease. Patients may feel guilty, particularly if their carers or members of their family lose benefits because of the loss of their DLA while in hospital.

- Patients who lose DLA/AA and other linked benefits because of the in-patient rules may experience delays in having their benefit reinstated. This can lead to further financial hardship.

- Patients are generally unaware of the in-patients rules, or are unable to understand their complexity. Those who do know may take drastic steps to avoid losing benefits as result of the rule. Some may feel driven to withhold information from the DWP. In rare cases, patients may even compromise their treatment to avoid losing DLA or AA.

- The exacting nature of cancer treatment, and the high frequency of in-patient stays, can make it difficult for patients to keep the DWP informed about the length of their hospital visits. This may result in overpayment of benefit, which patients may find difficult to pay back.
**Special Rules for terminal illness:**
- The Special Rules can work fairly well for cancer patients, although certain aspects of the criteria for eligibility, and the processing and administration of claims, can cause problems.

- There is wide variation in doctors’ interpretation of the six-month life expectancy definition of terminal illness. Doctors’ difficulties in predicting patients’ life expectancy can make them reluctant to supply a DS1500 to support the patient’s application under Special Rules.

- The six-month definition of terminal illness was considered too restrictive and thought to deter doctors from claims under Special Rules. A 12-month definition was thought to provide greater flexibility.

- Patients’ lack of knowledge about their prognosis makes it difficult for benefits advisers and the DWP to assess their eligibility under Special Rules. Patients’ denial of their prognosis may also prevent or delay them from claiming under Special Rules.

- Delays in the processing of claims under Special Rules are caused by:
  - the loss or mismatch of application forms and DS1500 forms when sent to the DWP separately from each other
  - submission of a DS1500 without a DLA/AA claim form
  - doctors’ delay in sending a DS1500
  - inadequate information from GPs, resulting in a rejection of the DS1500
  - doctors’ delays in responding to DWP requests for further information.

- Dedicated Special Rules units, staffed by well-informed and empathetic personnel, are thought to be particularly effective. However, not all regions have these.

- There is a lack of transparency in DWP decision-making. Patients don’t have access to the medical evidence supporting their claim, and don’t get personalised feedback if their claim is rejected. The shroud of secrecy inherent in the Special Rules process can create tensions and conflicts of interest for benefits advisers and contribute to obstructions to the processing of claims.

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**Recommendations**

Benefits advisers gave a number of suggestions to make the DLA/AA claims system fairer for cancer patients, the most popular of which are broadly consistent with Macmillan Cancer Relief’s policy calls. However, there are important differences in emphasis and nuance. Some study findings suggest the need for refinement of Macmillan’s recommendations for legislative change and provide policymakers with useful options for consideration.

A comparison was made between the suggestions of benefit advisers and Macmillan’s current policy calls in the light of the evidence from this study. This was used to formulate proposals for refining the recommendations and proposing a wider range of policy solutions firmly grounded in the reality of cancer patients’ experiences and that of the benefit advisers who support them. These are:

- **Provide specialist benefit advice for cancer patients.** However, thought needs to be given to how such a specialist advice service should be provided, who should give it, and how it should be funded.
- Waive the retrospective and prospective tests for DLA and give cancer patients immediate fixed term awards for six to 12 months with review, subject to the normal care and mobility tests. This would presume in favour of the patient and help to address the specific care and mobility needs of people with cancer, who have immediate needs in the wake of diagnosis and treatment but whose long-term needs are fluctuating and unpredictable.

- Remove the six-month retrospective test for AA or align it with the three-month qualifying period for DLA. This would eradicate discrimination against the elderly, who have to wait longer than younger patients to receive benefit.

- The 28-day hospital downrating rule should be either scrapped altogether, the downrating rule aligned with other benefits (which are currently downrated after 52 weeks), or DLA and AA should be downrated after three months.

- The 28-day linking rule should be scrapped, or changed by halving the 28-day gap currently required between hospital stays to ‘break the link’. This latter suggestion would accommodate the characteristic three-week treatment cycle undertaken by many cancer patients.

- Extend the legal definition of terminal illness to 12 months. This would give doctors greater confidence to predict their patients’ life expectancy and widen the net of cancer patients considered eligible to apply, reducing the financial hardship and distress caused at the end of their lives.

- Review the accessibility and effectiveness of cancer-specific information and guidance currently available to DWP decision-makers, and identify areas for improvement.

- Review the effectiveness of DWP quality control measures and explore other mechanisms to improve the consistency and transparency of decision-making.

- Provide GPs and consultants with better information, support and resources to help improve their understanding of the DLA claims system and make more consistent assessments of their patients’ eligibility for DLA and AA.